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A Participatory and Creative Exploration of Autistic Young People's Experiences of Loneliness

Luciana Lisboa White

Submitted in accordance with the requirements for the degree of

Doctor of Philosophy

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School of Education, Language and Psychology

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The candidate confirms that the work submitted is their own, except where work which has formed part of jointly authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

The work in Chapter Three of the thesis has appeared in publication as follows:

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Abstract

This PhD project explored experiences of loneliness for autistic young people and consisted of three studies. In a systematic review, a critical reflection on traditional ways in which loneliness has been conceptualised and investigated showed that loneliness has rarely been defined by autistic young people and that meaningful connection is usually said to be limited to social relationships. The review also summarised available assessment tools of loneliness and belonging with critique of their design and suitability for autistic people. These findings pointed to the need for a revised definition of loneliness that should include subjective autistic experiences. The second study was a creative exploration of the experiences of loneliness for autistic young people through a qualitative and participatory design. It aimed to search for autistic understandings of loneliness, aligned with the neurodiversity paradigm and parting with predominant neurotypical frameworks of loneliness. The project also addressed how 'not being lonely' feels, by exploring autistic-led strategies that promote feelings of connection and well-being. The findings expanded the concept of loneliness as we know it. Autistic young people described loneliness beyond the social and emotional domains, including less studied facets of existential, experiential and positive loneliness. Equipped with a revised definition of loneliness, the third study focused on the theoretical development of a loneliness scale in collaboration with autistic young people and the people who support them. ELSA – Experiences of Loneliness Scale for Autistic Young People is a 52-item scale distributed into six domains. The scale goes beyond the assessment of how adequate relationships are and appreciates experiences of feeling misunderstood and different, offering insights into systemic factors that might increase feelings of loneliness. ELSA contributes a conversation starter and an evaluation tool for people who support autistic young people to better understand their experiences of loneliness with a focus on quality of life.

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Introduction

This research project is about the experiences of loneliness for autistic young people. Grounded in the neurodiversity paradigm, this thesis adopted creative, flexible and participatory approaches to data collection in order to amplify the voices of autistic young people and produce outcomes that were meaningful to the autistic community. In doing so, the thesis was multidisciplinary and integrated perspectives from the research areas of loneliness, adolescence and autism. These areas of research have their own disciplinary perspectives and methodologies and the way they have been conceptualised, studied and understood have changed through time under different historical, cultural and economic contexts. In this introduction, the concepts of loneliness, adolescence and autism are discussed, delineating the perimeter and scope of this research project and showing the lenses through which these concepts have been explored and understood. This is followed by the aims and research questions that guided the project and its main contributions. A summary of how the thesis was organised closes the introduction.

What is Autism?

The definition of autism has evolved over time, reflecting shifts in diagnostic, theoretical and social-cultural contexts. Its conceptualisation can vary depending on the perspective of who is producing it, and this is important because each perspective will have different implications for research and practice (Cherewick & Matergia, 2024). If understood as a disorder, the focus will be on a cure, if understood as a disability, the emphasis will be on accommodating needs and if it is framed as a neurological difference, the focus shifts towards understanding autism as part of natural human variation.

According to the National Autistic Society (2026), a charity for autistic people and their families in the United Kingdom, autism is understood as a neurological difference and disability that presents itself in as many ways as there are autistic people. Chapman (2020),

an autistic scholar in the field of neurodiversity defines autism as “natural and valuable manifestation of human genetic diversity (albeit disabled by society)” (p. 219). Historically, the definition of autism and its understanding have gone through changes since its first description in the early 1800s (Donvan & Zucker, 2016). From being considered a form of child schizophrenia in the 1950’s to its present characterisation (Cook & Willmerdinger, 2015; Evans, 2013), the perceptions of autism have changed, as has the way autistic people position and advocate for themselves in society. This section explores the historic evolution of autism, broadly from a medical perspective to alternative views of how it can be understood and investigated; it defines the concept of autism that is used throughout this thesis.

The Medical Model

Until very recently, autism was primarily studied through a neuropsychological lens, where behavioural indicators are the basis for diagnosis. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DMS-V-TR) (American Psychiatric Association, 2022), autism is defined as Autism Spectrum Disorder and the diagnostic criteria includes deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviours used for social interactions (such as little use of reciprocal eye contact) and deficits in maintaining and understanding relationships. Stereotyped movements (such as hand flapping and echolalia), lack of flexibility, fixated interests and hyper or hypo reactivity to sensory input are also part of the diagnostic criteria. The International Classification of Diseases (ICD-11) (World Health Organisation, 2019) places autism under neurodevelopmental disorders and characterises it by persistent social and behavioural deficits. In the ICD-11 autism is considered a spectrum condition that can present with or without intellectual disability and with or without impaired functional language.

Under these definitions of autism, there are different diagnostic tools used to determine whether someone is recognised as being autistic. These assessments are commonly based on external manifestations of behaviours (such as eye contact, facial expressions, and tone of voice) rather than internal experiences (Murray et al., 2023). For example, the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), considered the gold standard for diagnostic evaluation of autism (Kamp-Becker et al., 2018) uses semi-structured prompts and activities that primarily serve to identify and evaluate difficulties in social and communication skills. In contrast, phenomenological accounts of being autistic focus on subjective lived experiences and frame social and communicative differences as meaningful and context dependent (Murray et al., 2023). This perspective emphasises autism as a 'form of life' or a 'neurotype' with its own strengths and challenges.

Both characterisations of autism offered by the DSM-V-TR and ICD-11 are situated within a medical model of disability, whilst phenomenological accounts of autism are commonly situated within the neurodiversity paradigm. The medical model conceptualises disability as a problem located in the individual and emphasises diagnosis and treatment (Shakespeare, 2013). Critique of the medical model of disability argue that it assumes a dichotomy between normal and abnormal, where disability is regarded as inferior and differences are seen as deficits within the autistic person (Kapp, 2019).

Investigations anchored to these principles have produced research that asks about ways to change the behaviours or appearances of autistic people to fit in with societal conventions. Examples include quantitative evaluations of interventions aimed at 'treating' autistic people, such as the use of pharmacological interventions reduce restrictive and repetitive behaviours (Zhou et al., 2021). An example is the use of interventions to improve eye contact for autistic children (Demirtaş & Besalti, 2026). Other examples include studies with a focus on how to improve social skills in autistic people, offering an abundance of

therapies and interventions that have been tested and promise the development of social competence (Silveira-Zaldivar et al., 2021), social skills (Bohlander et al., 2012), social responsiveness (Factor et al., 2022), social-emotional reciprocity (Ip et al., 2024), to name a few. Influential authors have commented that this perspective alone fails to bring the subjective experience of the autistic person to the fore, as worthy of scientific value (Botha, 2021; Kapp et al., 2013; Milton, 2012; Walker, 2026).

The main focus of the medical model is to cure the deficit, fix the impairment, making the autistic person behave as close as possible to the way a neurotypical person does (Bottema-Beutel et al., 2021). From the perspective of autistic people, behaving according to imposed 'typical' social norms can lead to feelings of pressure to provide acceptable social and emotional responses, exclusion from the social fabric, aversion to being in social spaces, negative judgement towards aspects of themselves and disablement from meaningful participation in social contexts. Societal expectations to behave 'typically' have been discussed from autistic perspectives and findings suggest that hiding or obscuring autistic behaviours and/or traits to blend in with neurotypical behaviours can affect identity, belonging and anxiety (Atkinson et al, 2025; Larochelle-Guy et al., 2025). A study by Petty et al. (2025), co-produced with autistic people, described examples of how autistic rituals can be changed or hidden to avoid negative judgement from others. Participants mentioned "clicking a pen, completing a mental ritual in private, or leaving the room to say something aloud" (p. 7) as strategies to conform to the majority. Being made to fit in with neurotypical norms is described by Sinclair (2010) as an experience that might include misunderstanding and misinterpretation from both sides.

Hiding or changing behaviours due to societal pressure has been called masking (Pearson & Rose, 2021), camouflaging (Hull et al., 2017), compensation (Livingston & Happé, 2017) and adaptive morphing (Lawson, 2020). According to Price (2022), masking

"is a messy and unstable scaffolding of flawed coping mechanisms" (p. 98). Price's description refers to the higher levels of stress that autistic people have when they report masking or switching between masking/not masking. This stress is explained by Pearson and Rose (2021) as the result from the disconnection from one's identity. The societal pressure to fit in and behave according to pre-established norms described in this section has been widely reported. Both empirical literature (Botha et al., 2022; Howe et al., 2023; Ross et al., 2023) and personal accounts written by autistic people (Cook, 2018; Katy, 2025; Poe, 2020; Prahlad, 2017; Price, 2022) describe these experiences as stressful, exhausting, and possibly associated with negative mental health outcomes.

The Social Model and the Neurodiversity Paradigm

The neurodiversity paradigm offers an alternative perspective to understanding autism. The birth of the term 'neurodiversity' was influenced by the disability rights movement which developed from the 1960's and applied civil rights concepts to the discrimination and segregation of disabled people (Owens, 2015). The work of rights-based authors (e.g. Albrecht, 1992) challenged medicalised views and focused on how people were disabled by social contexts. The movement's slogan 'Nothing about us without us' and its conceptual debates provided new ways in which to think about autism and autistic people. Despite neurodiversity being a concept that changes often due to the complexities it evokes, it has become "epistemologically useful" (Chapman, 2020, p. 219). This means the term has helped people access and generate new forms of knowledge that can influence how people relate to autistic people, or how research and public spaces are designed.

The social model of disability challenges the binary concept of normality and abnormality adopted by the medical model and contributes a different way in which to conceptualise autism (Owens, 2015). The model recognises social barriers that can promote disability, but it also acknowledges inherent weaknesses of autism, understanding impairment

as a form of human diversity (Bottema-Beutel et al., 2021). The social model of disability states that, the perception of 'normal' is culturally constructed and far from being biologically proven (Walker, 2026). Under this model, disability is in the eye of the beholder. It is not only seen as a result of physical, cognitive and/or neurological impairment, but more as how a given condition is socially imagined. Being disabled is determined by social or environmental circumstances, such as physical environmental barriers (e.g., loud and busy classrooms), communication barriers (e.g., expectations of verbal communication or eye contact), and institutional or structural barriers (e.g., rigid teaching and assessment methodologies in schools). Within this perspective, autism has been defined as a spectrum of developmental conditions, which presents itself in different ways (Autistica, 2023).

Within the spectrum, some authors argue that there are individuals who are able to lead lives with minimal support, while others require more and/or specialist support, based on impairment categorisations from mild to severe (Weitlauf al., 2014). However, when autism is conceptualised as a social disability that includes multiple presentations, authors suggest moving beyond predefined levels and types of support and instead centring on what it means to be autistic for each individual (Anderson-Chavarria, 2022). A study exploring community perspectives on the types of support that should be on offer has highlighted autistic participants' views on the importance of improving quality of life through social change rather than through interventions aimed at changing the autistic person (Waddington et al., 2024).

Autistic Perspectives

According to descriptions authored by autistic people, autism is characterised as a particular way of being in the world which is neurologically different from the majority of people who are 'neurotypical' (Botha et al., 2022). Being autistic has been described as isolating "My whole life I had thought that I was from another planet, that someday the ship

would come for me and take me home" (Prahlad, 2017, p.3). It can bring social challenges and feel unfair "I'm a person for whom social nuance is absent. That's key. That's autism. Yet publicly and privately, I'm still expected to navigate the minefields deftly" (Cook, 2018, p. Xix). It has also been described as a unique way of being and navigating the world "I understood that I had a rich inner life, and I swam in it as often as I was able" (Gadsby, 2022, p.151). For some, receiving an autism diagnosis can be the start of self-acceptance and positive identity building "...autism was the first label stuck on me that made sense. It was like a weight had been lifted. Like the dark clouds swirling above my head had been brushed away, leaving skies of clarity" (Katy, 2025, pp. 185-186).

Sinclair (2010) also gave a few practical examples of how autism can present: some autistic people are highly verbal, but not orally fluent and will be more comfortable with written forms of communication, while others will not verbally communicate at all. Equally, some individuals will be 'sensory-defensive', finding sensory experiences overwhelming and difficult, while others will be sensation-seeking. Other examples given by autistic people include feeling physically and verbally immobilised (often labelled as 'shutdown') when overwhelmed or overloaded (Paris et al., 2025). 'Meltdowns' have also been described as a temporary loss of control that can be expressed verbally, physically or both (e.g., screaming, crying, kicking, biting) (National Autistic Society, 2026). All these sensations will vary for the same person depending on environmental factors, levels of stress, or how predictable stimuli are. This variability is also reflected across individuals and being autistic can feel different for each person, as personal narratives illustrate (Botha, 2021; Cook, 2018; Gadsby, 2022; Grandin, 2009; Katy, 2025; Poe, 2020; Prahlad, 2017; Price, 2022;).

Prahlad (2017) also adds that differences in autistic people's characteristics go beyond neurological differences; a significant number of autistic people are also dealing with a host of other co-occurrent conditions and neurodivergences. These include, but are not limited to,

abnormal metabolism, anxiety disorders, attention-deficit/hyperactivity disorder (ADHD), auto-immune disorders, bipolar disorder, depression, epilepsy, neuroinflammation, obsessive compulsive disorder (OCD), psychosis, schizophrenia, sensory disorders and Tourette's syndrome. This adds to the complexity of autism, further contributing to the wide variability in how it presents and is experienced.

Definition of Autism for this Research Project

As discussed above, it is important to examine the varying perspectives of what it means to be autistic due to their implications for research and practice. Beyond shaping research and practice, these perspectives also contribute to the master narratives of autism. These are the stories that are collectively and culturally shared; they give meaning to personal experiences and influence how phenomena are interpreted (McLean & Syed, 2016).

Master narratives are seen as “enduring parts of the structure of society” (McLean et al., 2018, p. 633) and can shape personal stories and influence identity development. Individuals can resist or internalise master narratives when telling their own stories and developing their identity (McLean & Syed, 2016). The way gender, race, sexual orientation and disability are framed by master narratives can have a strong influence on an individual’s agency and identity development. An example of a master narrative of disability is given by Chapman (2023) when they discuss how disabled people can feel devalued in a capitalist society that has binary narratives of the body as a working/non-working or a productive/non-productive machine. Similarly, pathologising master narratives of autism have been reported to generate more ableist cues, dehumanisation and objectification of autistic people; whereas master narratives of neurodiversity have been shown to include participatory methods more often and predicted lower odds of ableist cues (Botha et al., 2022).

This section did not approach every available perspective of what autism is, and the views discussed here certainly do not represent every autistic person. The uncertainty around a definition of autism means that it should be constantly revisited and updated. Definitions need to be responsive, considering autistic people's experiences both in personal contexts or when generalisable insights are being formulated. Fletcher-Watson (2026) explains that the point of diagnostic labels is that they "evolve, stretch, expand and encompass diverse ways of being that are nonetheless also unified by some indefinable shared core" (p. 5).

For this thesis, autism was understood as a neurodivergence, rather than a disorder. Under this view, characteristics and behaviours associated with being an autistic person in the world are considered as 'differences' rather than deficits. The design of the three studies was aligned with the neurodiversity paradigm and social model of disability. This was done by centring autistic perspectives through the use of participatory research and co-production methods, by focusing on lived experience and by framing disability as being within social and environmental contexts rather than within the individual. The findings contribute to the body of research that promotes shifting perceptions of disability and help to build more positive master narratives of autism, fighting stigma and promoting quality of life.

What is Loneliness?

Loneliness has been defined as a subjective human emotion which we are all susceptible to feeling sometimes (Willock et al., 2012). This section explains how loneliness has been commonly conceptualised as a bidimensional construct in research and suggests a rationale for a more comprehensive approach, based on how diverse representations of loneliness can be.

Loneliness has commonly been conceptualised in research as the negative feeling that results from a discrepancy between a person's *perceived* and *actual* levels of social

connection (Perlman & Peplau, 1981). In other words, loneliness is understood as a negative feeling that comes when we recognise that our social needs are not being met (Hawkley & Cacioppo, 2010). This conceptualisation stemmed from Weiss's (1973) seminal work, which identified two dimensions of loneliness: 1) social loneliness is defined as the perception of having an inadequate social network; 2) emotional loneliness is defined by dissatisfaction with the quality of social connections. These definitions were widely adopted in research and used as a theoretical framework for the development of many measures of loneliness, such as the UCLA Loneliness Scale (Russell et al., 1980) and the Loneliness Scale for Children (Asher et al., 1984). Examples of scale items that were designed and tested to assess the social and emotional domains of loneliness include "There are people I feel close to", "I lack companionship" (Russell et al., 1980) and "I have lots of friends", "I have nobody to talk to" (Asher et al., 1984). Whilst these conceptualisations and measures of loneliness contributed significantly to the understanding of its core dimensions, they do not encompass the complexity of the construct or how it is experienced by different groups of people (Fried et al., 2020).

Loneliness has been studied across disciplines including history, literature, anthropology, art (Barclay et al., 2023; Cooper et al., 2024), philosophy (Kierkegaard, 1992; Nietzsche, 2009; Sartre, 1943), neuroscience (Cacioppo & Hawkley, 2009; Eisenberger, 2012), gerontology (Hawkley et al., 2008; Victor et al., 2022), education (Goossens & Maes, 2017; Qualter et al., 2021;), psychology (Hawkley & Cacioppo, 2010; Perlman & Peplau, 1981; Moustakas, 1961), sociology (Weiss, 1973), as well as within public health (Holt-Lunstad et al., 2015; Valtorta et al., 2016), and varying socioeconomic contexts (Luhmann & Hawkley, 2016).

Loneliness has also been used as a motif in literature, art, poetry and music. For example, Franz Kafka (2009) explored physical and emotional isolation, as well as alienation

from family and society in his book The Metamorphosis, first published in 1915. Van Gogh's (1888) famous painting "The Bedroom", suggested his personal solitude in a depiction of his own quiet and still bedroom. Edgar Allan Poe in 1829 expressed emotional and existential loneliness in his poem "Alone" (Poe, 2026). Loneliness is also widely represented in pop-culture with many artists and bands, from The Beatles (1966) to Adele (2015), singing about social and emotional isolation, alienation, separation and longing for connection. Historically, the definition of loneliness has evolved from a feeling of dread for being physically isolated from society (and open to harm) to a modern epidemic, where people are surrounded by others and still feel subjectively lonely (Worsley, 2018).

Despite loneliness being portrayed in art, literature and popular culture as complex and multifaceted, psychological research has often conceptualised and measured it in more restricted ways. In academic literature, despite existential loneliness being empirically recognised as significant from youth to older adulthood, it has received less attention than social and emotional loneliness (McKenna-Plumley et al., 2023). The issue with this is that there is an assumption of how loneliness is felt and experienced. For example, in a meta-analysis of interventions used for alleviating loneliness in young people (Eccles & Qualter, 2021), 14 studies were included. Out of these 11 focused on interventions to improve social skills, increase social interaction and enhance social support. Two studies included psychological therapies and one focused on social identity and acceptance. These results suggest a tendency on assessing and addressing loneliness as if it was limited to the social and emotional domains.

For autistic young people, experiences of loneliness are less well understood. Many autistic young people have expressed their desire to have and maintain friendships (Gallup et al., 2016; Murphy et al., 2017; Myles et al., 2019), however, some autistic young people describe pursuing friendships in order to be considered 'normal' (Berns, 2016) or prefer

spending time alone (Goodall & MacKenzie, 2019). Early research by Bauminger and Kasari (2000) added further understanding to the complexity of the experiences of loneliness for autistic young people; they reported that having a best friend does not seem to lessen feelings of loneliness for autistic children, raising questions as to what contributes to meaningful experiences of relationships, connection and belonging. Subsequent research has reinforced this complexity. Although autistic individuals define friendships similarly to their non-autistic peers, they also mention unique challenges to developing and maintaining social relationships, including differences in social norms and communication style (Black et al., 2024). Anxiety, fear of judgement and a poor self-image might also compromise the development of relationships in which autistic people feel accepted and authentic (Black et al., 2024).

Further support for this interpretation comes from research examining loneliness interventions. A review on the effectiveness of loneliness interventions (Lasgaard et al., 2026) suggested that psychological interventions appeared to be the most effective strategy while those interventions focusing on improving social skills and supporting social networks were less efficient in reducing loneliness. Psychological interventions were considered more effective as they can address many psychological processes associated with loneliness rather than simply increasing opportunities for social interaction. This indicates that feelings of loneliness cannot be fully explained by social and emotional domains alone, and that measuring instruments could be missing important nuances of the construct by only focusing on these dimensions. In line with this argument, Grace et al. (2025) found that loneliness for autistic adults is not solely determined by unmet social needs, but also by the lack of shared experiences with the wider population and a lack of understanding of autism in society. These findings strengthen the understanding of loneliness as a multidimensional concept.

Definition of Loneliness for this Research Project

The diversity of representations of loneliness and connection together with the gaps in understanding of autistic young people's experiences of loneliness and connection, suggest that loneliness might be experienced in various ways across different domains. Understanding the complexity of loneliness calls for more inclusive and broader definitions, a point explored in the first two studies of this thesis. The first study aimed at finding definitions of loneliness authored by autistic young people and the second study explored how autistic young people experience loneliness and connection.

In line with its critical orientation, this thesis adopted an understanding that there are multiple realities of loneliness (Gedvilaitė-Kordušienė, 2018). From the beginning, it was assumed that autistic young people might feel lonely, and they might not. They might also feel lonely to different extents over different times and places, with different people and things. It was also assumed that autistic people might feel lonely in ways that are similar to or different from their non-autistic peers. The exploration of the topic was not limited to the widely used frameworks of social and emotional loneliness predominant in research. Inspired by the many ways in which the construct has been represented in the arts and discussed particularly in philosophical literature, this thesis focused on the multidimensional nature of loneliness and on exploring its many facets. A more detailed description of the theories that underpinned the understanding of loneliness can be found in Chapter One, where the theoretical background for the thesis is discussed.

What is Adolescence?

This section examines how the concept of adolescence has evolved and how it is still an ongoing topic amongst society and scholars. It shows how the use of physical and behavioural markers together with social and economic contexts have helped to shape the

concept. The parameters used to establish the cohorts relevant for this thesis are also discussed in this section.

The concept of 'adolescence' was introduced in the United States in the second half of the 19th century, influenced by the increase in secondary school enrolment, young people's prolonged education and a reduction in labour-force participation (Kett, 1993). This definition considered not only the social and economic changes of the time but also physical and behaviour changes typical of this phase, such as puberty and character traits (Hall, 1905). Adolescence has widely been defined as the phase that corresponds to the onset of puberty and goes to the point when the individual is considered legally an adult and independent from their guardian (Jaworska & MacQueen, 2015), roughly starting at 12 and going to 18 years of age (Dahl, 2004). More recent definitions of adolescence tend to go beyond markers of biological growth, brain development and social roles, also focusing on other influences that might alter current perceptions of when adult life begins (Sawyer et al., 2018).

The term has evolved but its start and duration are still topics of debate amongst researchers (Sawyer et al., 2018). In recent years, from a biological point of view, earlier puberty has been present across many populations, and brain development and growth endpoints have both been understood to extend well into a person's 20s (Arain et al., 2013; Casey et al., 2005; Rogol et al., 2000). From a social perspective, there has been a delay in when young people complete their education, get married and become parents. In current society, there are strong forces of marketing and negative effects of social media use that can be detrimental to health and wellbeing, sometimes prolonging the need for emotional support from parents (Beckwith et al., 2024). These later milestones might then extend how long a person is considered to be (or remain) an adolescent dependent on their academic accomplishments, marital and professional statuses. Considering all these aspects of human development Sawyer and colleagues (2018) proposed extending the period of adolescence

from 10 to 24 years of age, as they argue this corresponds more closely with how this phase of life unfolds in terms of biological, psychological and social transitions in contemporary western society. Although this extended understanding of adolescence has been well accepted and applied especially in health research (Azzopardi et al., 2024; Baird et al., 2025), it is not used universally. According to the World Health Organization (WHO), adolescence is the phase between childhood and adulthood that goes from 10 to 19 years of age (World Health Organization, 2025). This age range is also adopted by the UK government in health policies (Viner, 2012). The term 'young people' has also been used both in research, health and world organisations to define the period of transition between childhood and adulthood (ERIC, 2024). The United Nations (2025) define "youth" as the period going from 15 to 24 years of age.

In autism research, age ranges tend to vary greatly, and scholars are not consistent in adopting a definition of adolescence. The systematic review conducted as the first study of this thesis showed that studies that used terms such as 'adolescents', 'youth' and 'young people' had samples ranging in age from 7 to 27 years (Lisboa White et al., 2024). Some examples of studies include Daniel and Billingsley (2010) with a sample of males from 10 to 14 years old, Foggo and Webster (2017) with a sample of females from 13 to 17 years old, Haegele and Maher (2022) with a sample of males from 13 to 18 years old, Gallup et al. (2016) with a sample of males from 16 to 21 years old and Feldhaus et al. (2015) with a sample of males from 15 to 27 years old. The studies do not offer a justification for these age ranges or a description of adolescence but adopt terms such as 'teenage years' (Feldhaus et al., 2015), 'autistic young students' (Haegele & Maher, 2022), 'adolescents and young adults' (Gallup et al., 2016), 'mainstream secondary school students' (Foggo & Webster, 2017) and 'boys' (Daniel & Billingsley, 2010) to describe young people transitioning from childhood to adulthood.

Definition of Adolescence and the Adoption of the Terminology 'Young People' for this Thesis

Initially, the age range for this thesis was defined based on more traditional biological and social understandings of adolescence, ranging from the onset of puberty, at approximately 12 years old, to when the individual becomes legally independent, at 18 years old (Jaworska & MacQueen, 2015). This age range was adopted for the first study of the project, the systematic review. However, the age range was adjusted for the second and third studies from 12 to 24 years old, following suggestions from autistic young people who participated in a familiarisation meeting held to recruit collaborators. They recommended extending the upper limit to 24 years old, to capture the perspectives of individuals who were still in education and not yet fully independent. Although a final definition of adolescence was not reached, the suggestions from autistic young people to extend the age ranges emphasised the importance of maintaining a flexible social and biological understanding of adolescence throughout the research project. Consequently, the term 'young people' was chosen to describe the study samples, as it is more inclusive and less prescriptive than 'adolescents'.

Research Questions, Aims and Summary of Main Findings

The purpose of this research project was to explore how autistic young people experience loneliness and connection. By using creative and flexible methods, alongside autistic collaboration, the thesis centred autistic voices with the aim of adding autistic perspectives to the literature on loneliness and connection. The thesis was organised into three studies and the research questions, aims and summary of main findings will be discussed in turn.

Study One

The first study was a systematic review of literature on how autistic young people self-reported experiences of loneliness and connection. The objective of the review was to understand what was already known about the topic. This study was guided by the following research questions: a) how do autistic adolescents describe loneliness? What do 'lonely' and 'not lonely' feel like?; b) how is loneliness measured and reported in research with autistic adolescents?; c) what strategies are used personally by autistic adolescents to promote meaningful connection and wellbeing?

The main findings of this systematic review were that loneliness has rarely been defined by autistic people and that connection has been limited to social relationships (i.e., friendships). These findings reflect a typical way of understanding loneliness with little recognition of autistic experiences, reinforcing a historical trend of defining autism based on social deficits (Milton et al., 2023). Another important finding was that the scales that have been consistently used to investigate loneliness for autistic young people are standardised scales based on concepts that do not include autistic views. This suggests that there is an assumption that loneliness is experienced similarly by autistic and non-autistic people. The findings of this systematic review pointed to the need for a revised definition of loneliness that should include subjective autistic experiences, wide participation of the autistic community and exploration of strategies that are personally meaningful to autistic young people.

Study Two

Based on the findings of Study One, Study Two was designed with the main aim of asking autistic young people how they experience loneliness. This was a qualitative exploration with the following research questions: a) how do autistic young people

experience loneliness?; and b) what personal strategies promote feelings of connection and wellbeing?

The main findings of Study Two contributed an extended conceptualisation of loneliness. This included how feeling 'not lonely' is perceived and a more extensive exploration of personal strategies used to foster feelings of connection. In this study, loneliness was described by autistic young people as going beyond the well-known social and emotional domains and included less studied facets of existential, experiential, and positive loneliness. A critical evaluation of these findings based on the ontological shift in autistic research (Milton, 2012; Sonuga-Barke, 2023) suggests that to better understand these experiences of loneliness described by autistic young people, we might have to move our focus from the individual to the behaviour of communities and societies.

Study Three

Equipped with a new understanding of loneliness that included autistic perspectives, the purpose of Study Three was to design a loneliness scale for autistic young people that was named Experiences of Loneliness Scale for Autistic Young People (ELSA). The research questions that guided Study Three were a) what scale items represent loneliness for autistic young people?; b) are the proposed scale items clear and easy to understand?; and c) is the scale appropriate for autistic young respondents?

The main contribution of Study Three was the theoretical development of the ELSA, containing 52 items that assess six domains of loneliness.

How the Thesis is Organised

The thesis was organised to reflect the PhD project chronologically. It starts with two chapters discussing the theoretical and philosophical assumptions adopted, followed by three studies, each presented in a separate chapter. Between chapters three, four, five and six, there

are bridging sections that summarise key findings and main contributions and indicate how they inform the subsequent chapter. The thesis closes with an overall discussion and a reflexivity chapter.

Summary of Chapters

Chapter one offers an overview of the theoretical background of loneliness and its conceptualisation, focusing on psychological theories that supported the multidimensional and dialogical framework adopted throughout the investigation.

Chapter two presents the philosophical underpinnings of this thesis. Ontological and epistemological positionings are discussed, focusing on the ontological shift in autistic research and the participatory research methods adopted with the aim of enabling epistemic justice.

Chapter three presents Study One of the thesis, a systematic review. This study involved an examination of the literature to identify what was currently known about the experiences of loneliness for autistic young people.

The first Bridging Section summarises the findings of Study One and how they contributed for the design of Study Two. The section also outlines the direction of Study Two.

Chapter four reports the findings of Study Two, a qualitative and creative investigation of the experiences of loneliness and connection for autistic young people. The chapter details the participatory methods that were used during the study design including participatory data analysis.

The second Bridging Section summarises the findings of the first and second studies and how they contributed for the design of Study Three. The section also outlines the direction of Study Three.

Chapter five details the theoretical development of a loneliness scale for autistic young people in collaboration with scholars, clinicians, parents and autistic young people. The chapter describes the four phases of the study including the process of item generation and refinement.

The third Bridging Section summarises how Study One and two provided the foundation for the development of Study Three. It also outlines the main findings and contributions of Study Three.

Chapter six provides a general discussion of all findings demonstrating how one study informed the next, highlighting the overall coherence of the thesis. The chapter focuses on how the investigation progressed from the systematic review of the literature to the theoretical development of the ELSA, outlining the rationale underpinning the choice of methods in line with ontological and epistemological positionings.

Chapter seven offers a reflexivity report, structured into three subsections addressing personal, functional, and disciplinary reflexivity. The chapter is a personal reflection on how these dimensions influenced the design of the research project and the interpretation of the findings.

Chapter 1: Theoretical Background

This thesis adopted a multidimensional conceptualisation of loneliness. This approach expands more traditional views of loneliness, that despite being widely accepted by researchers and forming the shared understanding of loneliness in western cultures, are limited to two domains: social and emotional loneliness. This section offers the theoretical rationale for choosing this multidimensional approach and explains how this aligns with the ontological and epistemological positions that have guided this research project.

Traditional conceptualisations of loneliness describe it as the feeling that arises from the discrepancy between how a person perceives or evaluates their actual levels of social connection (Perlman & Peplau, 1981). This negative feeling is the result, therefore, of a cognitive assessment and the recognition of a gap between what is desired and what is real. Although not explicitly stated, this notion of loneliness seems to adopt a Cartesian conceptualisation of the self. This framework establishes the self as individualised, self-contained and separated from the body and the world (Hermans, 2001). In the Cartesian model, loneliness can be seen as the result of an autonomous cognitive appraisal of relationships and social connection. The self is a rational and self-reflective observer (Taylor, 1989) that measures and interprets experiences related to social connection. Within this model, loneliness is understood as a mental state generated by an internal evaluation rather than relational or collective processes.

Alternatively, the psychological model developed by Hermans (2001) adopts a dialogical approach and sees the self as an embodied collection of multiple *I*-positions engaged in ongoing dialogue. The Dialogical Self Theory evolved from Bakhtin's philosophy of language, that sees the self and meaning as relational and emerging from the dialogue with others: "To be means to be for another, and through the other, for oneself. A person has no internal sovereign territory; he is wholly and always on the boundary" (Bakhtin, 1984, p.

287). From this point of view, intersubjectivity exists not only between people, but also within the self: “The self functions as a society of mind, in which intersubjective positions are located both within and outside the person” (Hermans, 2001, p. 248). This constant internal dialogue between the multiple aspects of identity, means the self remains relational even in the absence of others.

The implication of adopting this dialogical approach is that loneliness can be reframed as a space of internal connection rather than disconnection from others. It brings more nuance and complexity to the understanding of what might constitute ‘feeling lonely’ or ‘feeling not lonely’. Rather than being the result of an objective appraisal of an emotion as the Cartesian model suggests, loneliness would emerge from a relational assessment of the many different dialogues an individual has with others and with parts of the self. In other words, under a dialogical understanding of the self, loneliness shifts from an individual deficit or from the absence of social contact to a relational disruption, a breakdown in internal and / or external dialogues that can be multiple and conflicting all at once. Disruptions in external dialogues could include feelings of social exclusion, misunderstanding or lack of reciprocity when interacting with other people. Disruptions in internal dialogues could include the loss of the multiple internal voices (internal polyphony) (Hermans, 2001).

Locating loneliness within intersubjective or dialogical processes is relevant for understanding the experiences of loneliness for autistic young people. It allows for an understanding that autistic young people might experience loneliness positively and as a space where they can concentrate on their personal interests and be authentic. This means that feelings of loneliness are not exclusively limited to the absence of social relationships or to their quality, and therefore the social and emotional domains of loneliness are not fully representative of the ways in which someone can feel lonely. If someone feels positively lonely, for example, this means they remain engaged in internalised forms of communication,

where the multiple internalised voices that constitute the self sustain a sense of connection even in the absence of others. At the same time, a person might recognise that parts of themselves do seek connection with others or evaluate this to be a cause of upset.

A dialogical view is also useful for understanding loneliness as shared construction between others and the self. Whereas the Cartesian model places loneliness within the individual, reducing it to a cognitive gap, the dialogical model suggests that loneliness emerges through intersubjective relations with the self and with others. Reconceptualising loneliness through these lenses means that if a person feels unseen, misunderstood or judged – as some autistic young people describe existential and experiential loneliness – it signals a breakdown in the reciprocity that constitutes both self and society. This idea suggests a shared responsibility for loneliness. It cannot be only down to the individual to make connections, but societies are also responsible for creating contexts in which diverse voices can be heard (Hermans, 2001; Milton, 2012). This would also include recognising ways in which people feel positively lonely.

Understanding loneliness through the Dialogical Self Theory was important for this thesis as it aligns closely with contemporary and major ontological shifts in autism represented by Milton's (2012) Double Empathy Problem. Milton challenged the assumptions that difficulties in social understanding or connection reside within an autistic individual and located them historically and culturally in discourse. This means that the misunderstandings between autistic and non-autistic people are bidirectional rather than a deficit on the autistic side. What connects the dialogical framework and the double empathy problem is the assumption of a redistribution of responsibility (for promoting connection and alleviating loneliness) and the transformation of the available dialogues within society.

Chapter 2: Philosophical Assumptions

This chapter outlines the philosophical assumptions that underpinned this research project and how they impacted on the choice of methods and the adoption of a participatory approach.

Ontology

Ontological positions describe the nature of reality (Braun & Clarke, 2022b). In other words, ontology underpins the assumptions made about the nature of the phenomenon being investigated. In autism research, ontological positioning defines what autism is, its nature and the assumptions around what exists in relation to autism. This influences the questions that are being asked and how findings are being interpreted (Crotty, 2015; Hodge & Runswick-Cole, 2008).

In the Introduction of this thesis, the section 'What is autism?' explored some of the complicated history of autism and how it was first studied almost exclusively as a psychiatric disorder (Donvan & Zucker, 2016). These first denominations of autism and its consequent investigations were oriented by a realist, biomedical or essentialist ontology that assumed an objective truth, waiting to be discovered (Braun & Clarke, 2022b). Practices aligned with this ontology were focused on developing diagnostic tools, genetic investigations, and interventions to cure autism (Botha & Cage, 2022). More recently, studies in the humanities and social sciences, together with efforts from autistic activists and writers, have focused more on lived experiences (e.g., Higgins et al., 2021; Hurlbutt & Chalmers, 2002; Lockington & Gullon-Scott, 2025) and on how social inequalities can shape autistic lives (Pellicano et al., 2018). This constitutes a major shift in perspective, going from a medical, deficit-based approach to a diversity-based approach to understanding autism. These investigations – interested in promoting quality of life, environmental adaptations or understanding how social interactions can shape autistic life – align with a critical realist ontology. Under this

orientation the assumption is that reality exists but not without context and/or perspective (Braun & Clarke, 2022b). In other words, our reality is socially located and mediated by language and culture (Pilgrim, 2014), rather than being one single truth ready to be revealed by objective and systematic methods (Burr, 2015).

This project was conceived under a critical realist orientation, which is compatible with how the neurodiversity paradigm defines autism and how the dialogical self-theory defines the self. Contrary to the medical model of disability, that pathologises autism as a disorder and promotes stigmatization of autistic people (Legault et al., 2024), the neurodiversity paradigm offers an alternative perspective. It focuses on the obstacles that autistic people face and the inadequacy of physical and social environments for autistic people (Pellicano & den Houting, 2022), or the mismatch between neurodivergent differences and neurotypical expectations (Shaw et al., 2025). Under a critical realist lens, this means that neurological variations are real and acknowledged, but the meanings and values attributed to these differences are socially constructed and influenced by our interpretations. This ontological stance was also applied to the understanding and interpretations of loneliness. Loneliness was framed as having real dimensions, such as social exclusion and social and emotional isolation. However, loneliness was assumed to be experienced by the self within social, cultural and relational contexts, as well as language.

Radical shifts in perspective are hard to achieve, especially when concepts such as autism and loneliness have been consolidated by cultural ideologies and social discourses. It is difficult to reframe views because it requires a transformation in fundamental assumptions which might include redefinition of terms, calibration of language, reinterpretation of data and reformulation of basic concepts and how to approach them (Walker, 2026). Autism research started a shift in perspective by re-evaluating ontological stances that did not produce meaningful outcomes for autistic people. The pathological framing of autism and its

categorisation as a neurological disorder, justified by the binary concept of normality (normal, or not) have been challenged by many activists and autistic scholars (e.g., Bascom 2012; Botha, 2021; Kapp et al., 2013; Milton, 2012; Ne'eman, 2010; Walker, 2026). Their efforts are bringing new understandings to what being autistic means by shifting the ontological status of autism. This thesis was inspired by and based on these views.

Epistemology

Epistemological positioning relates to how and by whom knowledge is generated and it considers the meaning and validity of knowledge production (Braun & Clarke, 2022b). Epistemology is closely related to ontology and for autism research this means that knowledge has been for a long time produced and validated by non-autistic people largely aligning with a medical model of disability (Krawczyk et al., 2025). This approach has been said to dismiss autistic subjective experiences (Milton, 2012) and has made autistic people the object of research, with 'problems' that need fixing (Botha & Cage, 2022). The prevalence of a medical model paradigm in autism research, led by non-autistic researchers with limited input from autistic people, has also had an influence on what kind of knowledge is produced and consequently funded. Emphasis has been given to knowledge around biological, neural and cognitive aspects of autism, rather than understanding and promoting autistic wellbeing (Pellicano et al., 2014). A common issue with this kind of research is that it can assume objective 'truths' about autism and autistic people without acknowledging the epistemic limitations of not including autistic subjective knowledge. Another point to be considered is the use of designs that do not include autistic perspectives. For example, the use of standardised scales that assume 'typical' experiences and require responses that might be inadequate for autistic people (Nicolaidis et al., 2019). Another example is the use of interview formats that require a specific type of interaction from participants, such as verbal answers (Harrington et al., 2014). Although standardised and prescribed methods carry the

"weight of convention" and are "culturally embedded as the most reliable" (Cook, 2021, p. 1), they can produce stigmatising outcomes that do not help and are not meaningful for the autistic community, contributing to what Botha and Frost (2020) discuss as 'minority stress'.

Meaningful knowledge can be generated when ontological and epistemological assumptions that pathologise autism and exclude autistic perspectives from research are addressed (Harrington et al., 2014; Legault et al., 2024). This requires centring autistic perspectives and subjective experiences and empowering autistic communities to be included in knowledge production, by validating research questions, designing projects and disseminating outcomes (Fletcher-Watson et al., 2021). Adopting participatory research methods and co-production by involving autistic people as integral collaborators in knowledge production is an alternative to the exclusionary epistemic approaches mentioned above (May, 2024). In addition to representing autistic people in research, the adoption of participatory methods reshapes how knowledge is accessed and produced. When the 'reality' of being autistic– and of forming meaningful connections with others and the world – is understood as continuously constructed, rather than fixed, different forms of knowledge are created.

The same principles of participatory research apply for the inclusion of young voices in research. Young people's voices have often been under-represented, in part due to non-inclusive traditions of research and ethical challenges (Santos & Meneses, 2010). Including young people's perspectives, especially when investigating topics that might inform public policy, has been considered an important strategy to improve health practices and research guidelines (Alves et al., 2022). The relationship between the participants and the researcher, the framing of questions and the way in which participants can respond become central to the production of this knowledge.

Participant engagement can also contribute to broadening and democratising the knowledge that is produced. Creative methods of participation can enable engagement and empower collaborators to add their views to research (Kramer-Roy, 2015). With their emancipatory aims, creative methods empower collaborators to shift dominant views by producing counter-narratives within a safe research context where participants can feel comfortable and confident about their contributions (Lenette, 2022). In addition, they can include the perspectives of people who use or prefer alternative forms of communication that go beyond traditional verbal or written methods. The use of visual materials (photography, drawings and collage), embodied techniques (drama, body-mapping and imaginative play) music and poetry (Kennedy & Brewer, 2016; Lewis et al., 2021; Lewis et al., 2024; Teti et al., 2016), have been successfully used to increase representation and inclusion in disability and autism research.

Flexibility is equally important when it comes to accommodating preferences and individual needs. Ridout (2017) used creative and flexible methods of data collection to understand how a group of autistic people conceptualised their experiences of being autistic and found that this design choice made the research more inclusive by embracing diverse communication preferences.

This thesis was guided by principles of participatory research and co-production and used creative and flexible methods as part of its epistemological stance. Combined with a contextualist approach, knowledge production focused on autistic lived experience, researcher reflexivity, and ‘truths’ that were considered partial, situated and perspectival (Braun & Clarke, 2022b). In the section below, a more detailed description of the methods used for participatory research and creative methodologies is offered.

Participatory Research

Participatory Research has been defined as a collaborative process used to include people with lived experience as co-creators of knowledge (Abma et al., 2019; Cook., 2021). It constitutes an attempt at embracing the complexities of social contexts by engaging with different assumptions and knowledges (Cook, 2021). Participation within this framework means the sharing of power between participants and researchers on the decision-making process (Bratteteig & Wagner, 2016). That could involve decisions related to study design, data collection and analysis, evaluation of results and dissemination of findings.

Participatory approaches were incorporated across the three studies in different ways and to varying degrees to incorporate perspectives of autistic young people and the communities that support them. This was an effort to include autistic perspectives in the understanding of how loneliness is experienced and to address epistemic injustice in this field of research. For example, this included knowledge exchange and up-skilling of research contributors (Fletcher-Watson et al., 2021), which meant that researchers learned from autistic young people's lived experience and autistic young people learned about the research process. Meaningful involvement of autistic people and members of the neurodivergent community not only broadens the research agenda and improves research impact, but it has also been argued to greatly increase ethical and epistemological integrity of studies (Chown et al., 2017; Milton & Bracher, 2013; Shaw et al., 2025). This means conducting research in a way that is just and responsible towards the community by including commonly unheard voices, recognising lived experience as valuable knowledge and avoiding one-sided accounts and interpretations.

Following this rationale, the participatory approaches used in this research sought to create opportunities for autistic people to influence the research and to recognise their lived experience as a legitimate form of knowledge, while acknowledging that there were

institutional and academic constraints that meant that not all differences in power between researcher and participants were balanced. Reflecting on these boundaries, making them explicit and considering how different forms of knowledge are recognised and afforded credibility, is important when considering epistemic justice (Fricker, 2007). Recent work in neurodivergent research has similarly emphasised the value of making different forms and levels of involvement explicit, rather than treating participation as a binary condition (Pavlopoulou et al., 2025; Fletcher-Watson et al., 2024; Sonuga-Barke et al., 2024). In this thesis, participation is therefore understood as a continuum of involvement rather than a single methodological category. Table 1 makes visible where contributors were consulted, where they could influence research decisions and interpretations, and where final authority remained with the academic researcher.

Table 1

Levels of Participatory Research Used in This Thesis

Study/Stage	Who Contributed	Level of Participation	Influence	Remained with researcher	Academic recognition
Study 1 (design)	Autistic people and those who support them.	Consultation	Relevance and framing of research aims/questions.	Final research design and definition of research questions.	Acknowledgement in the publication / not listed as authors.
Study 2 (design)	Autistic young people (18+).	Collaboration	Design of methods and ways of contributing data.	Overall study design and methodological decisions.	Acknowledgement in the publication / not listed as authors.
Study 2 (data collection)	Autistic young people (12-24).	Data contribution.	Mode and manner of contribution.	Research questions, facilitation and data management.	Recognised as knowledge contributors / not listed as authors.
Study 2 (data analysis)	Autistic young people who contributed data.	Collaborative analysis.	Interpretation of data and coding.	Final analysis and synthesis.	Recognised as collaborators / not listed as authors.
Study 2 (evaluation of preliminary findings)	Autistic young people who contributed data.	Consultation	Feedback on preliminary interpretations (themes).	Final interpretation and refinement of themes.	Recognised as collaborators / not listed as authors.

Study/Stage	Who Contributed	Level of Participation	Influence	Remained with researcher	Academic recognition
Study 3 (refinement of candidate items)	Autistic people and those who support them.	Collaboration	Feedback on relevance and clarity of candidate items.	Final scale construction.	Recognised as collaborators / not listed as authors.
Study 3 (pre-testing)	Autistic young people (12-24).	Collaboration	Response range, and style, wording and order of items.	Final scale construction.	Recognised as collaborators / not listed as authors.

Participatory design (Abma et al., 2019; Chown et al., 2017; Cook, 2021; den Houting, 2021) was adopted throughout this work in the following ways, by 1) inviting autistic people and those who support them to validate research aims and questions for the systematic review; 2) inviting autistic people to contribute to Study's Two design; 3) inviting autistic young people who had collaborated data to Study Two to participate in data analysis and evaluation of preliminary results; and 4) inviting autistic people and the communities who support them to contribute to the theoretical development of the ELSA during Study Three.

Creative and flexible methods of research (Ridout, 2017; Lewis et al., 2024) were used in the following ways: 1) autistic young people and those who support them could choose to contribute remotely or in-person; 2) contributions could be done by writing, typing, or talking; 3) creative methods of data collection in Study Two included semi-structured interviews, art-based interviews and posting comments on an anonymous virtual wall of thoughts; 4) sessions were flexible by including breaks, pre-arranged schedules, and by allowing participants to decide when to stop their contributions. Participatory, creative and flexible methods encouraged autistic people to engage with research; however, this involvement did not come without its challenges.

During the process of recruiting autistic people to participate in this research project as experts in autism, a certain resistance was found. Recruitment was challenging for both consulting and participant roles. From the 26 participants who contributed data to Study Two, 11 chose to take part in the first phase of data analysis. Out of these, nine came back for the second phase when they were asked to evaluate preliminary results. Schools and charities that were contacted to facilitate recruitment were in most part unresponsive. Five autistic young people who initially had put themselves forward to collaborate with the development of the scale in Study Three had a change of mind before sessions took place. Historically, autistic people have often been positioned as passive objects of study rather than active participants in knowledge production (Botha, 2021; Milton, 2014a). Many choose to participate only when the research is truly collaborative and includes fair payment for their time and expertise. Although legitimate and just, these requirements are hard to achieve with the very limited budget of researchers, the difficulty in securing funding for participatory research and the tax and benefits implications for participants in the UK (Lambley, 2025). Improvements in the research culture are slowly starting to happen, led especially by the health research field. The National Institute for Health and Care Research (NIHR) in the UK, for example, encourages engagement and participation in research (NIHR, 2024), however, opportunities are limited and dependent on several requirements. Funding applications can be long, complicated and laborious, and not always available to projects that are part of a PhD programme.

The challenges faced were not limited to recruitment but also included broader difficulties in sustaining ongoing engagement with partners, especially due to the time constraints of the PhD. Continuous engagement with communities and the building of long-term relationships between researchers and stakeholders are often advocated as requirements for ethical and effective participatory research (Reed et al., 2014). Constant dialogue ensures

that the researcher is in touch with shifting community needs and research that remains relevant and sensitive (Stover et al., 2024). Despite the limitations, efforts were made to remain connected with community partners, which proved meaningful and effective in sustaining ongoing relationships. This included returning to community events and responding to invitations from partners to contribute to activities such as judging an art competition during neurodiversity week, disseminating findings through a school newsletter, contributing to a college impact report, and delivering a talk on neurodiversity to students. Although informal, these activities promoted continued dialogue and reciprocity, supporting relationships. At the same time, efforts to involve participants more directly in dissemination included invitations to co-present or contribute to presentations. These were however, declined, which illustrates the ongoing practical challenges of sustaining community involvement.

Enabling Autistic Involvement Through External Funding

Despite the challenges it was possible to incorporate autistic involvement and engagement at several stages of this thesis thanks to two external grants. The grants were used during studies two and three. For Study Two, groups of autistic adults were invited to contribute to the design of creative and flexible methods of data collection to engage autistic young people. After data was collected through these methods, autistic young people were invited to participate in the data analysis and evaluation of preliminary results. Participants' evaluation of the coding highlighted nuances in the dataset that enhanced and deepened the formulation of themes. Later, participants were invited again to evaluate the creation of themes and preliminary findings of the study. These sessions were funded by a grant offered by the Waterloo Foundation (Appendix A).

The third study was the theoretical development of a loneliness scale for autistic young people, the ELSA, and the study was divided into four phases. Each phase was

designed to incorporate feedback from autistic people and the communities that support them into the refining of scale items. These sessions were funded by a graduate grant offered by the Organization for Autism Research. Detailed descriptions of the participatory methods adopted at each stage will be discussed in Chapters Four and Five, where studies two and three are presented respectively. These descriptions can be found under sections titled 'Community Involvement'.

Positionality Statement

This section contextualises the thesis by exploring the researcher's positionality and considering how it has both supported and shaped the research. Recent discussions within autism research emphasise that acknowledging positionality is an epistemological and ethical practice. Fletcher-Watson (2024) argues that transparent author positionality supports more accountable and participatory research cultures, particularly in fields where lived experience is central to shaping meaningful inquiry. Similarly, Tan et al. (2025) highlight how researcher positionality can strengthen community engagement and improve the relevance and accessibility of research for autistic participants. First person was used to reflect how the researcher's experiences shaped knowledge production.

Professional Background and Initial Conceptualisations

I am a non-autistic researcher with a professional background in education. I started my career as a primary school teacher and through working with children I became interested in how autistic young people experience relationships, belonging and loneliness, especially within educational contexts. My professional experiences also shaped my initial understanding of autism and loneliness. My practice was largely embedded in a medical model of disability, which conceptualises disability as a problem located in the individual and emphasises diagnosis and treatment (Shakespeare, 2013). I accepted this framing without

critical appraisal of it. Standardised measures and developmental benchmarks guided my understandings of children's development and behaviour and the work I developed in the classroom.

My understanding of loneliness was also initially aligned with more traditional conceptualisations that commonly frame loneliness only in terms of perceived deficits in social relationships. Under this conceptualisation, a lonely person feels they need to increase the size of their social network or the quality of their relationships. As I explored the subject in greater depth, I found a complex scholarly landscape and became aware that autistic experiences of loneliness were less well understood and did not always align with traditional conceptualisations. For example, Bauminger and Kasari (2000), reported that the presence of a best friend might not alleviate loneliness for autistic children. These findings prompted me to question the adequacy of dominant conceptualisations of loneliness for understanding autistic experiences.

Transition to Neurodiversity-Affirmative Thinking

At the start of the PhD, I was transitioning from professional practices informed by the medical model of disability towards more neurodiversity-affirmative approaches. This transition influenced how I understood autism and loneliness and required me to critically examine assumptions that I had previously taken for granted. In particular, I became increasingly aware of the risk of interpreting experiences such as spending time alone, having fewer social relationships or engaging in personal interests to a greater degree than other children as inherently problematic, without considering how these experiences were understood and contextualised by autistic young people themselves.

Engagement with participants' accounts and with wider literature further challenged me to critically examine dominant narratives of loneliness and traditional conceptualisations.

This contributed to my understanding of loneliness as a dynamic and multidimensional experience that extended the understanding of loneliness as a bidimensional concept. It also reinforced the importance of considering autistic young people's own understandings of their experiences rather than interpreting them solely through pre-existing psychological or educational frameworks. This transition also meant that I had to remain attentive to the possibility that my previous professional experiences could influence what I expected to find, noticed or prioritised in the full research design and in the data and its analysis and interpretation. Through consistent reflexive practice, I tried to remain open to ideas that challenged assumptions from my previous professional experiences and to forms of loneliness and connection that might not be readily recognised within traditional educational or psychological frameworks. This can be seen particularly in Chapters Four and Five, where I describe the qualitative exploration of loneliness and the development of the ELSA in collaboration with autistic young people. Engaging in participatory and co-produced approaches enriched my understanding, giving me access to perspectives I would not otherwise have encountered and prompting ongoing reflexive consideration of my own role, assumptions, and interpretive lens.

Positionality and Practical Aspects of the Research

My positionality also influenced practical aspects of the research, including my choice of methods, recruitment and relationships with participants. My position as a non-autistic researcher influenced my choice of methods and was one reason for adopting inclusive, flexible and participatory approaches. Participatory methods created opportunities for autistic young people to influence the research process and to communicate their experiences in ways that were meaningful to them. Their perspectives were not treated simply as data to which I applied pre-existing understandings of loneliness and connection, but as an important source of knowledge through which those understandings could be questioned and developed. This

reflexive stance was also an attempt to address epistemic injustice by ensuring that autistic young people's interpretations were treated as legitimate forms of knowledge (Catala et al., 2024; Nešić, 2023).

My professional experience in education also influenced my approach to recruitment and my relationship with participants. I am familiar with educational environments and with how young people often respond to adults in a position of power. I was also conscious of the potential for participants to perceive me through the lens of my professional role and this knowledge supported how I approached young people and built rapport. I therefore tried to distance myself from the 'teacher' position. Examples of how I did this included using my first name when introducing myself to young people, wearing informal clothes and showing curiosity about their preferences and interests. This is furthered detailed in the section 'Community Involvement' in Chapter Four.

Familiarity with educational environments and how they are structured also facilitated recruitment. I knew who to approach and, because I understood how busy schools are, I knew I had to be brief and efficient when presenting the project. This is also reflected in how I prepared materials to facilitate participation (Appendices F and G). I believe that being a teacher also opened doors, as my professional background provided a degree of familiarity and credibility within educational settings. However, I remained mindful that this familiarity also carried assumptions about young people. Therefore, I remained reflexive and used a reflexive journal that helped me to consider how my professional experience could be shaping interactions, interpretations, and the co-production process. Examples of this reflexivity can be seen in Chapter Four, Table 10.

My cultural background also informed my position within the research. I was aware that understandings of relationships, social participation, independence and belonging may be

shaped by cultural and educational contexts. The research was conducted within the UK, and the conceptualisation developed through the thesis is therefore situated within the cultural and educational contexts in which the research took place. Recognising these influences helped me to understand the findings as co-constructed within particular contexts.

These aspects of my positionality shaped how I initially understood loneliness and autism, how I approached participants and the research process, and how I interpreted the knowledge generated through the research. They are considered further in Chapter Seven, where I explore personal, disciplinary and functional reflexivity.

Chapter 3: Systematic Review

This chapter presents a systematic review of the literature, which was conducted to understand what was already known about the experience of loneliness for autistic young people.

Introduction

Loneliness has been conceptualised in many ways (Cramer & Barry, 1999; Motta, 2021). However, there is agreement that loneliness is part of human experience and that prolonged and persistent loneliness can be detrimental to health, mental wellbeing and cognition across the life span (Cacioppo & Hawkley, 2009; Deckers et al., 2017; Holt-Lunstad et al., 2015).

The systematic review was motivated by the assumption that autistic experiences of loneliness are less well understood. Higher rates of loneliness have been reported for autistic young people when compared with their peers (Deckers et al., 2017) and high levels of anxiety have been connected to feelings of loneliness in autistic young people (White & Roberson-Nay, 2009). Many autistic young people have expressed their desire to have and maintain friendships (Gallup et al., 2016; Murphy et al., 2017; Myles et al., 2019), although some describe pursuing friendships in order to be considered ‘normal’ (Berns, 2016). Bauminger and Kasari (2000) added further understanding to the complexity of the subject; they reported that having a best friend did not seem to lessen feelings of loneliness for autistic children, raising questions as to what does contribute to meaningful experiences of relationships, connection and belonging.

Interventions that support social skills have been used to address loneliness in autistic young people. These include music and drama sessions, Lego-based interventions and cognitive behavioural-based social interventions (D’Amico et al., 2015; Ghasemtabar et al.,

2015; Koning et al., 2013; LaGasse, 2014; Lindsay et al., 2017). Although there is evidence that social skills training can reduce feelings of loneliness and can foster belonging for autistic young people (Gantman et al., 2012), other findings suggest that offering social skills training, or interventions to increase opportunities for social contact, can be inappropriate for autistic people (Bottema-Beutel et al., 2018). For some autistic young people, navigating expectations of neurotypical communication, such as initiating or reciprocating social interactions, interpreting non-literal speech, and / or managing sensory processing sensitivities, can lead to efforts to imitate a particular way of socialising that detract from their sense of self (Causton-Theoharis et al., 2009; Mesa & Hamilton, 2022a). These social obstacles can contribute to experiences of rejection, exclusion, and distress (Tierney et al., 2016). Some autistic young people respond to constant expectations to be more 'sociable' by masking or camouflaging to appear more like their neurotypical peers (Tierney et al., 2016), whilst others withdraw from social invitations (Wainscot et al., 2008). These coping strategies could be contributing to mental ill health, as they are described by autistic people as being "exhausting and associated with feelings of anxiety, stress, sadness and identity confusion" (Cook et al., 2021, p.3). This means that although social skills interventions are commonly used to reduce loneliness for autistic young people, their effectiveness is mixed. Whilst for some autistic young people they promote feelings of belonging, for others, they feel like pressure to conform to 'typical' social norms, exacerbating feelings of loneliness, exclusion and distress.

One aim of this systematic review was to investigate how autistic young people have described being 'not lonely'. Some of the known personal strategies described by autistic people to soothe distress and feelings of loneliness include turning within and using imagination and fictional companions as a substitute for social connection (Causton-Theoharis et al., 2009), creating imaginary and personified friends (Davis et al., 2018) and

anthropomorphising (Caruana et al., 2021). The systematic review aimed to explore these approaches further, identifying autistic-led strategies that can promote feelings of connection, belonging and companionship.

In summary, a need for understanding how autistic young people experience loneliness was identified, indicating that loneliness and connection might be experienced differently by autistic young people when compared with their non-autistic peers. This systematic review sought to answer the following questions: (i) How do autistic young people describe loneliness? What do 'lonely' and 'not lonely' feel like? (ii) How is loneliness measured and reported in research with autistic young people? (iii) What strategies are used personally by autistic young people to promote meaningful connection and wellbeing?

Methods

This study was pre-registered on PROSPERO (CRD42022374504). The review followed the updated guidance (Page et al., 2021) of the preferred reporting items for systematic reviews and meta-analysis (PRISMA). The steps for completing the systematic review involved extensive search of literature, location and quality appraisal of the findings. This was followed by the synthesis of included literature related to the topic of loneliness and connection for autistic young people.

Ethical approval was received from the School of Education, Language and Psychology Research Ethics Committee at York St John University (RECPSY00058). The panel commended the use of a PPI group and the consideration of potential ethical issues.

Community Involvement

Guided by the framework for emancipatory research in the field of autism (Chown et al., 2017) and guidelines for participatory and inclusive autism research (den Houting, 2021; Fletcher-Watson et al., 2019), a patient and public involvement (PPI) group with members of the autistic community guided the research process. The group was composed of two mothers

of autistic adolescents, who also identified as being neurodivergent and two experienced teachers. One was a specialised teacher for autism, and the other was a Special Educational Needs Coordinator (SENco) in a primary school setting. Consultation with the PPI group refined research questions and informed the search strategy for the review. Some of the most significant points discussed by the group are summarised below.

The PPI group acknowledged the relevance of the research topic and the need to know more about the experiences of loneliness for autistic young people, emphasising that matters related to wellbeing should come before academic attainment. They mentioned how feelings of loneliness can affect school attendance and how loneliness is commonly understood from a neurotypical point of view. Differences in communication and interpretation of social dynamics as well as lack of inclusive practices in school were named as things that might increase loneliness. Comments on the strategies used to soothe feelings of loneliness were varied, with teachers emphasising social skills interventions and parents highlighting the importance of validating personal strategies. Everyone agreed on the importance of family support and parents recognised the great value of having pets. As general guidance for the project, members of the panel highlighted the importance of understanding every autistic person as being unique and remembering that autism can occur alongside other disabilities that could aggravate loneliness.

Defining Adolescence

Adolescence is the transition between childhood and adulthood and has widely been defined as the phase corresponding to the onset of puberty and until an individual is considered legally an adult and independent from their guardian (Jaworska & MacQueen, 2015). This is usually determined as being between 12 and 18 years of age (Dahl, 2004). Researchers apply age ranges inconsistently; therefore, the systematic review search strategy was broader than ‘adolescent’ search terms to allow full text review (Table 2). Studies with

quantitative designs were excluded if participants were predominantly younger than 12 years or older than 18 years. For qualitative designs, when relevant quotes from participants could be identified as being from someone between 12 and 18 years of age, these studies were retained.

Eligibility

The review sought qualitative descriptions of loneliness and connection as experienced by autistic young people, authored by any stakeholder. Qualitative, quantitative and mixed-methods designs were included. A mixed-methods approach helped to develop an overarching picture of inherently complex topics (Stern et al., 2020).

Inclusion and exclusion criteria (Table 1) were developed from SPIDER concept maps (Boland et al., 2023) to identify descriptions of loneliness, measures of loneliness and personal strategies that promote connection and wellbeing. Although the Population, Intervention, Comparison, Outcome tool (PICO) is popularly used in systematic reviews and can efficiently retrieve quantitative research, it lacks sensitivity for qualitative and mixed-methods research (Cook et al., 2021). The Sample, Phenomenon of Interest, Design, Evaluation and Research type tool (SPIDER) presents additional categories that relate to 'design' and 'research type', increasing its ability and sensitivity to identifying qualitative and mixed-methods titles (Methley et al., 2014).

Table 2

Inclusion and Exclusion Criteria Developed from SPIDER Concept Maps

Study Criteria	Include	Exclude
Sample	Autistic adolescents between 12 and 18 years of age	Autistic individuals younger than 12 or older than 18 years of age
	Autism Autism Spectrum Disorder	Schizophrenia ADHD

	Autism Spectrum Condition Asperger's syndrome Aspie Pervasive disorder ASD ASC	ADD Down Syndrome William's Syndrome
	Adolescent Teenager Middle School Young adult Youth Secondary School Young people KS3 (Key Stage 3) KS4 (Key Stage 4) High School College A Level	Adult Toddler Young children Early Years KS1 (Key Stage 1) KS2 (Key Stage 2) Elementary School University Higher education Middle Age Elderly Old
Phenomenon of **I**nterest	Descriptions of loneliness from any stakeholder including the development of measurements of loneliness (assessment tools or scales) Strategies used by autistic young people to promote connection and belonging or to reduce loneliness Original measures of loneliness (such as self-reported measures; scales that assess loneliness for autistic people)	
Design	Interviews Focus-groups Surveys Questionnaires Diary entries Blog entries Photo elicitation Other creative methods Development of measures of loneliness	Systematic reviews Meta-analyses Scoping reviews
Evaluation	Definitions of meaningful social connection Original measures and reports of loneliness developed for autistic people	Outcomes that are not related to loneliness or connection (example: improvements in social skills)
Research Type	Qualitative Content Analysis Phenomenology Interpretative Phenomenological Analysis Mixed Methods Thematic Analysis Ethnography Grounded theory Narrative Analysis Quantitative	

Initial searches were conducted in early 2023 and update searches just before publication, in September 2024. Following good practice from previously successful systematic reviews (Francis et al., 2022) a scoping exercise was conducted to inform eligibility criteria. This preliminary search indicated that relevant studies had been published between 2000 and 2022. In addition, the pioneering research by Bauminger and Kasari (2000) became a pivotal study in the field and, therefore a good starting point for relevant publications around the experience of loneliness for autistic young people.

Search Strategy

Guided by Aromataris and Riitano (2014), key terms from the research questions were identified with the aid of the SPIDER table (Boland et al., 2023) which specified the sample, phenomenon of interest, design, evaluation and research type that would be significant for the review. This was followed by the creation of conceptual maps with key terms (Table 3). Alternative terms were lifted from relevant literature, dictionaries and thesauruses. The complete list of search terms was carefully considered and refined by discussions with supervisors. Boolean search strings were created and combined in three different searches that were consistently used across all databases (Table 4). Some databases required adaptations which consisted of using the same combination of words without truncation.

Table 3

Generation of Key Terms Based on Research Questions

RQ: How do autistic adolescents describe loneliness? What does 'not lonely' feel like for autistic adolescents?

	Sample	**P**henomenon of **I**nterest	**D**esign	**E**valuation	**R**esearch type
Key terms	Autistic adolescents	Descriptions of loneliness	Interview Focus-groups Surveys Questionnaires	Connection	Qualitative Mixed methods Quantitative Grounded theory Content analysis Thematic analysis Narrative analysis Interpretative phenomenological analysis Phenomenology Ethnography Creative methods
Search terms	Autis* ASD ASC Asperge* Pervasive*disord* Adolesce* Teenag* Young adult* Youth Young people Student* Young person	Social Isolat* Withdraw* Reject* Exclu* Companion* Alone* Lone*	Interview* Focus group* Survey* Questionnaire* Diar* Self-report* measur* Blog* Narrative* Stor* Autis* voic*	Friend* Pet Anthropomorphism Companion* Famil* Attachment Belong* Engag* Connect* Accept*	Qualitative Mixed method* Quantitative Grounded theory Content analys* Thematic analys* Narrative analys* Interpretative phenomenological analys* Phenomenolog* IPA Ethonograph* Creative method*

Table 4

Combination of Boolean Strings Used for Searching Literature for the Systematic Review

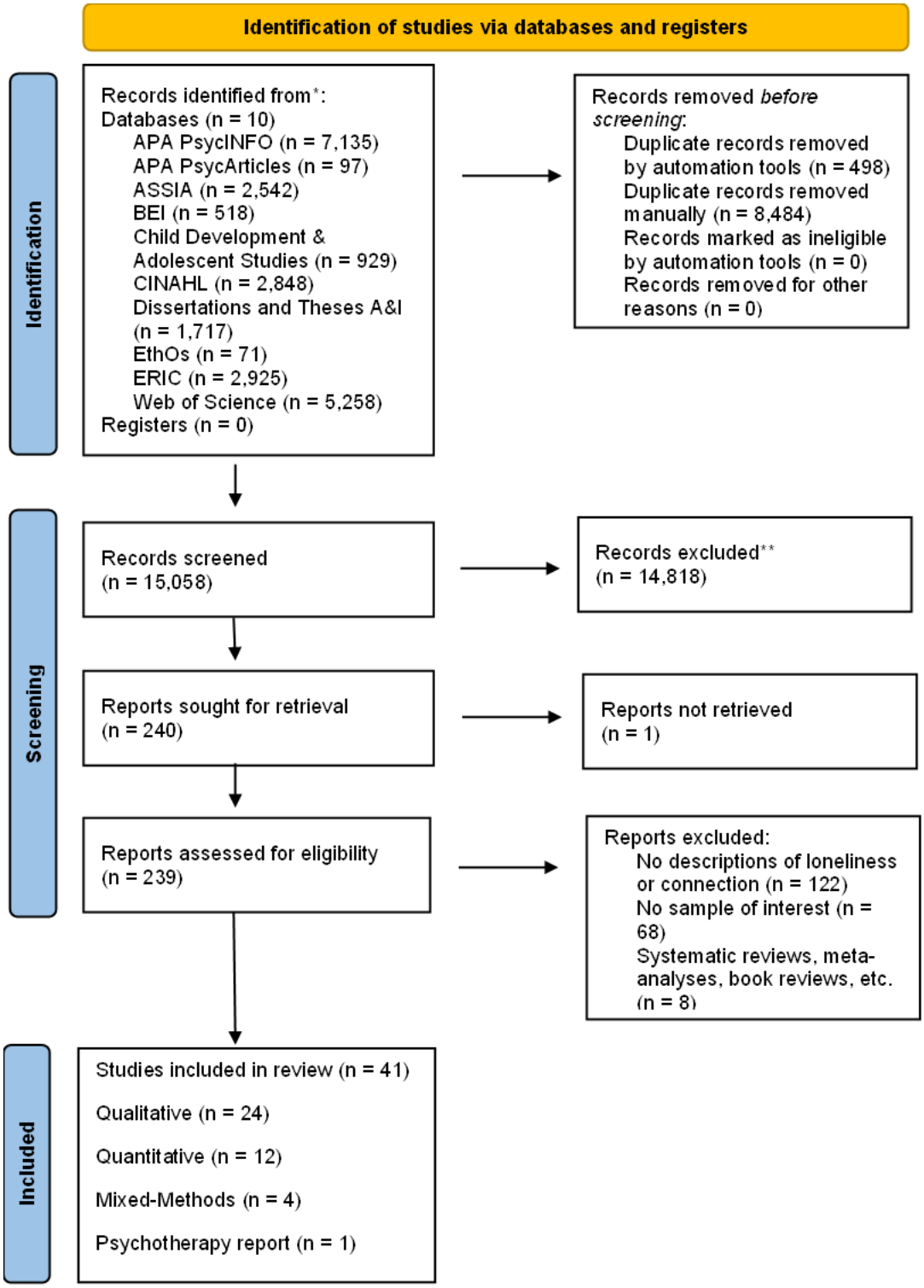
Search 1	Search 2	Search 3
Autis* or ASD or ASC or Asperge* or Pervasive*-disord*	Autis* or ASD or ASC or Asperge* or Pervasive* disord*	Autis* or ASD or ASC or Asperge* or Pervasive* disord*
AND	AND	AND
Social Isolat* or Socially Isolat* or Withdraw* or Reject* or Exclu* or or Alone* or Lone*	Loneliness scale* or LACA or UCLA or PNDLS or SELSA or LRS)	Social skill*
AND		
Friend* or Pet* or Anthropomorph* or Companion* or Famil* or Attachment or Belong* or Engag* or Connect* or Accept*		

Screening and Study Selection

The initial searches returned 24,040 titles. Titles were transferred to RefWorks and then to Rayyan (Ouzzani et al., 2016), an online tool that aids collaboration amongst researchers conducting systematic reviews. After automatic and manual deduplication, 15,058 titles were retained and submitted to title and abstract screening. 25% of titles and abstracts underwent a double-blind screening with the help of an undergraduate volunteer (ET) studying Cognitive Science at Dartmouth University (USA). The inclusion and exclusion criteria were shared and discussed during calibration meetings. Inter-rater reliability was substantial, k=.68 (95% CI, .61-.80). For the second phase of screening, 30 full texts were independently screened. Inter-rater reliability was moderate, k=.58 (95% CI, .41-.60). Disagreements during both phases were discussed in conjunction with supervisors. Reasons for exclusion are detailed in the PRISMA diagram (Figure 1) for the second phase of screening. After full text screening, 41 titles were included in the review.

Figure 1

PRISMA Flow Chart Diagram



Note. PRISMA 2020 Flow Diagram for Systematic Reviews adapted from Page et al. (2021).

The update searches conducted in September 2024 returned 2,573 titles. After deduplication, title and abstract screening, six titles were retained for full text screening and four were included in the review (Dean et al., 2023; Gerber et al., 2023; Schiltz et al., 2024; and Sumiya & Senju, 2023). These additional titles corroborate the findings around representations of loneliness in assessment tools.

Quality Assessment

To assess the quality of included titles, the Mixed-Methods Appraisal Tool (MMAT) (Hong et al., 2018) was used in consultation with supervisors. This tool was designed to evaluate different categories of research including qualitative, quantitative and mixed methods studies. It was chosen for this systematic review, as it acknowledges the unique methodological characteristics of studies included in mixed methods reviews (Hong et al., 2018).

Quality assessment of included titles started by submitting each title to two screening questions to determine if they could be further appraised by the tool. These questions were related to the clarity and presence of research questions and to the inclusion of data that allowed research questions to be addressed. Once these screening questions were done, each study was further appraised by being submitted to specific questions corresponding to its research design (e.g., qualitative, quantitative, and mixed methods). Examples of elements evaluated by the MMAT tool include coherence between data sources in qualitative research, the representativeness of the target population in quantitative research and an adequate rationale for the use of mixed methods designs.

There are three possible ratings for each of the questions that assess quality: ‘yes’, ‘no’ or ‘can’t tell’. Responding ‘can’t tell’ means that the title did not offer enough information or that the information given was unclear in relation to the criterion, making a

'yes' or 'no' response inappropriate. The MMAT guidance recommends avoiding the calculation of an overall score based on individual criterion ratings, as this may not accurately reflect the quality of the included studies (Hong et al., 2018). Instead, reviewers are encouraged to provide a more detailed assessment of included literature.

All 41 titles included after the first searches completed in early 2023 were grouped and assessed according to the guidance: qualitative (n=24), quantitative non-randomised (n=1), quantitative descriptive (n=14), and mixed methods (n=5). One title (Adamo, 2004) was not appraised as it did not fit any of the categories, but since it contributed personal voice from an autistic young person, it was deemed valuable and therefore included in the final sample. The four titles included after the update searches completed in September 2024 were also grouped following the same method: quantitative descriptive (n=3) and mixed methods (n=1).

Most qualitative titles were of excellent quality presenting clear research questions, with collected data and qualitative approaches allowing the research questions to be addressed. They also offered suitable methods and findings that were adequately derived from the data. Interpretations of results were, in most part, sufficiently substantiated by data, which led to coherence between data sources, collection, analyses and interpretation. Five titles were judged as having moderate quality (Acker et al., 2018; Danker et al., 2019; Kunz, 2009; Myles et al., 2019; O'Hagan & Hebron, 2017) due to several limitations, including insufficient information about methods, vague data extracts that made it difficult to determine whether the findings were appropriately derived from the dataset, and lack of clarity in the results section, particularly regarding how themes were generated.

One title was assessed under the quantitative non-randomised category (Wendler, 2018). This report had clear research questions, participants were representative of the target

population, measurements were appropriate, and the intervention occurred as it was intended. However, there were lots of missing data, no control group and confounders were not accounted for. Therefore, this was judged as being of moderate quality.

Fourteen titles were assessed under the quantitative descriptive category and 12 were of excellent quality. Two titles (De Gennaro, 2015; Nomura et al., 2012) were of moderate quality due to presenting insufficient information about sampling strategies and representativeness. None of the studies in this category offered information about the risk of nonresponse bias.

Five studies were assessed under the mixed methods category. Only one study in this category was considered of excellent quality (Dean et al., 2023) and overall, it was the category lowest in quality. This could possibly be due to the challenge of having more than one methodology to report and the additional requirement to offer an adequate rationale for using mixed methods. Two titles were of poor quality (Locke et al., 2010; Reynolds, 2017) as they failed to give enough qualitative evidence for the analyses and they lacked clarity when reporting methodology. In addition, they did not integrate qualitative and quantitative findings, nor did they point divergences. Reynolds (2017) did not adhere to the phenomenological approach they claimed to use. The other two titles in this category were of moderate quality (Bradley, 2016; Collier, 2018), just failing to report a rationale for using mixed-methods and for not discussing the inconsistencies between qualitative and quantitative data.

Quality appraisal was used to characterise how young people have been represented in research and to improve future research design. Given the infancy of this research area, it was important not to exclude young people's voices, therefore, all studies were included in the review.

Data Extraction

In qualitative content analysis, the data extraction process is key in understanding several aspects of the literature, as it allows the researcher to have their first insights around the dataset (Kyngäs et al., 2020). Research questions have a fundamental role in guiding the extraction, by helping the researcher to focus on what is relevant for their investigation. Data extraction was guided by the same SPIDER concept map which was used to generate search terms and inform the inclusion criteria. Extracted data consisted of title, author, year and type of publication, sample, phenomenon of interest, design, evaluation, and type of research. Main findings and discussion of the suitability of methods or accommodations made for autistic populations were also extracted.

Themes outlined by the author(s) were extracted for all qualitative papers. For example, one of the qualitative titles included in the review (Hall, 2021), had the outlined theme “Social barriers” extracted for analysis (p. 99), as this was related to a number of social challenges identified by participants as problematic for engaging socially and feeling connected. All qualitative descriptions of loneliness, connection and belonging were extracted from primary quotations, excerpts and summaries offered by authors. An example is this quote from a male participant who talked about his difficulties understanding social relationships: “I just stay on one level. I just can’t seem to go onto the next level for anything at all” (Hall, 2021, p. 100). Measures and scales of loneliness were extracted from all quantitative papers. Mixed-method papers had qualitative and quantitative strands analysed separately according to the description above. Extracted data were organised on a Word document and discussed during supervision meetings, making sure that relevant information was being selected and that rigour and consistency were maintained.

Synthesis

Data synthesis is the process through which evidence is organised, integrated, and interpreted producing new knowledge in response to the research questions (Gough et al., 2017). There are several methods for synthesising evidence from systematic reviews. Their suitability for a particular project will depend on many factors such as the complexity of the dataset, the research questions guiding the review and the objective of the synthesis (Petticrew & Roberts, 2006). These factors were considered when choosing how to synthesise findings for the present review and are discussed below.

Complexity of the dataset. 'Homogeneous' systematic reviews include papers that share the same design methodology, dependent variables and outcome measures (Haidich, 2010), often articulated as meta-analyses. These allow for quantitative summaries of variables that are used to address the research question (Petticrew & Roberts, 2006). For example, a meta-analysis conducted by Fracis et al. (2022) looked at the impact of play-based interventions on the mental health of children and adolescents with autism spectrum disorder and developmental language disorder. They identified 18 mental health outcomes within the 10 studies of their dataset. After conducting meta-analytic calculations, the authors concluded that play-based interventions have a significant overall effect on positive mental health outcomes, but not on negative mental health outcomes. These findings illustrate how a quantitative summary of variables can lead to important insights related to a specific research question.

When the included studies are more heterogeneous, a host of other methods of syntheses need to be considered to integrate different types of evidence. Heterogeneity in research evidence can be understood in terms of clinical diversity, methodological diversity and statistical heterogeneity (Deeks et al., 2023). An example of this type of synthesis was used by Coughlan et al. (2020) when they looked at identifying and managing care for

autistic children in general practice. Their conclusions illuminate a variation in both the way researchers conceptualise autism knowledge and general practitioners' knowledge of autism. In this example, the authors chose to synthesise the data thematically, rather than statistically, due to the diverse nature of the included studies.

Research Questions Guiding the Review. Reviews that are guided by more closed research questions usually benefit from methods that lead to statistical inferences and instrumental impact (Gough et al., 2017). For example, Xiong et al. (2023) evaluated the effectiveness of melatonin for insomnia in autistic children and found that melatonin has a certain effect on relieving sleep disturbances for these individuals. Their research question intended to test a hypothesis that was based on statistical methodology, therefore meta-analysis was suitable for the synthesis of evidence. When the review is guided by open questions that deal with emergent concepts, it needs an approach that will lead to new theoretical inferences that can offer a better understanding of the phenomena being studied (Gough et al., 2017). For example, Cresswell et al. (2019) used meta-aggregation to synthesise the findings across 10 qualitative studies in a systematic review about the experiences of peer relationships amongst autistic adolescents. This methodology was chosen by the authors as it follows rigorous models while embracing the nature of qualitative research approaches.

These considerations are particularly relevant to the present review and informed the choice of synthesis method as discussed below. Data complexity and the nature of research questions were considered during this research project. First, the systematic review included heterogeneous studies, opposing the pre-requisite for a meta-analysis. The final selection included qualitative, quantitative and mixed-methods research. The studies that were included to the review differed in the age range of participants that they represented (which varied with definitions of childhood, early and late adolescence). The contexts where experiences of

loneliness were experienced and understood also varied, with research being conducted with therapy clients, students in mainstream schools, within mentorship programmes, special education units, outpatient clinics, support groups, and community service centres. In addition, some included literature used participants enrolled in other clinical studies.

Second, this systematic review was guided by exploratory aims. Rather than testing a pre-existing theory by asking a closed research question, this review asked open questions aimed at creating new understandings and concepts around the experience of loneliness for autistic adolescents. The aim was to describe and characterise loneliness for autistic young people and map what is known about the topic (Sandelowski, 2000). By adopting this approach, the systematic review aimed to contribute novel understandings of lived experiences of loneliness and add to emerging concepts of loneliness and connection. Moreover, it could identify ways in which autistic people might deal with feelings of loneliness and frameworks used to measure loneliness for autistic young people. The method for synthesising findings had to facilitate the description of the dataset, thus summarising content and identifying its nuances and highlights. Narrative synthesis and qualitative content analysis (Finfgeld-Connett, 2014; Popay et al., 2006) appeared to be suitable methods for the review. Further considerations of the aims of the review influenced the final choice and are explored next.

Narrative Synthesis. Based on the diversity of the dataset, and a meta-analysis not being possible, several authors recommend narrative synthesis as an appropriate method for juxtaposing, integrating, and interpreting the findings from the studies included in a systematic review (Gough et al., 2017; Petticrew & Roberts, 2006; Popay et al., 2006). Although a common approach to synthesising evidence, methodological guidance on how to conduct narrative synthesis is still limited (Lisy & Porritt, 2016). Narrative forms of syntheses are still being developed, which means that methods are always being adapted and

reshaped (Ryan, 2013). Practical steps on how to perform a narrative synthesis are not always clear or fully reported by authors. Grace et al. (2022), for example, in their systematic review about loneliness for autistic adults, used a narrative approach to synthesise data. Key information that addressed the review questions was collated from included titles, but no other explanation of how this was achieved was given. Watson et al. (2013) also conducted a narrative synthesis in a systematic review about interventions for alcohol and drug problems in outpatient settings. The authors describe the creation of evidence summaries, but no details of the process are given.

Guidance on how to conduct narrative syntheses such as Popay et al. (2006) and Ryan (2013) are useful to determine the suitability of this approach. They offer advice on how to structure the analysis regarding the different elements that should be present (i.e., the development of a theory, development of a preliminary synthesis, exploration of the relationships in the data and assessment of the robustness of the synthesis). However, when it comes to operationalising these elements, instructions are minimal, especially for the novice researcher.

The challenge of using narrative synthesis for this systematic review emerged when trying to translate data from a large heterogeneous sample of studies into a common rubric to create a preliminary synthesis. The available guidance (Popay et al., 2006; Ryan, 2013) suggests the use of thematic analysis to identify patterns, relationships and recurring concepts across studies, enabling findings from diverse forms of evidence to be organised and integrated into a coherent narrative. This method would be focussed on examining behaviours or understanding how autistic people make sense of the processes and factors that influence loneliness (Braun & Clarke, 2022a). However, as discussed earlier, the objective of the systematic review was not to investigate processes, or sense making, but to investigate the literature, giving a descriptive and interpretative overview of what is known. Qualitative

content analysis seemed like a more appropriate tool to summarise the large dataset, generating findings that are related to the research questions and purposes of the research project (Drisko & Maschi, 2015).

Another reason to choose qualitative content analysis for synthesising data from this systematic review is related to the ontological stance adopted for this thesis. Aligned with the paradigm shift in autism research, one of the aims of this project was to incorporate autistic views into research and to produce outcomes that make a difference and have a positive impact for autistic people's lives. Qualitative content analysis can help to describe and clearly define content and context – it is an exploratory and descriptive tool that favours the search for new ways of looking at events (Drisko & Maschi, 2015).

Within the complex area of autism research, qualitative content analysis can bring some clarity by defining and developing concepts and building a model (Hsieh & Shannon, 2005) that explains and summarises how the experiences of loneliness for autistic young people have been felt and investigated until now. Also important, is the possibility of using the outcomes of the analysis as a starting point to extend the data into wider advocacy claims, showing how this type of analysis can inform practice and policy (Graham & McDermott, 2006). In this thesis, the use of qualitative content analysis offered a descriptive approach that painted a picture of the scholarly landscape related to the experiences of loneliness for autistic young people.

Qualitative Content Analysis. Qualitative content analysis is a methodology used to synthesise primary data, commonly used in nursing studies (Elo & Kyngäs, 2008). It can also be found in other research areas such as psychology (Pownall et al., 2023; Snell et al., 2014; Thyme et al., 2013), music cognition (Bullerjahn & Güldenring, 1994), female sexual health education (Javadnoori et al., 2012) and health research (Nicholas et al., 2017). Since the late

1980's, qualitative content analysis has been successfully adapted for the purpose of systematic reviews (Finfgeld-Connett, 2014). This section will offer a brief exploration of the origins of qualitative content analysis and its epistemological and methodological suitability for this review.

Qualitative content analysis has developed from the limitations of its quantifiable equivalent, quantitative content analysis (Drisko & Maschi, 2015), commonly used to describe and quantify phenomena (Elo & Kyngäs, 2008). Quantitative content analysis is based on a positivist research tradition, aiming at testing hypotheses by drawing on pre-existing theory (White & Marsh, 2006). Its focus is on counting the frequency of manifest content and using descriptive and inferential statistics to capture concepts and meanings from a dataset (Drisko & Maschi, 2015). When trying to capture alternative perspectives, this quantifying method can be limited in at least three dimensions (Kracauer, 1952). First, meaning is not always evident or disclosed (manifest); often, it is underlying and veiled (latent). Second, meaning is complex and contextual and therefore needs more than counts of word frequencies to be understood. Finally, meaningful content will not always be highly frequent within a dataset. Individual experiences can bring significant contents that appear only once. These can be overlooked or lost if submitted to a systematic approach of frequency counting, rather than a contextual analysis. On the other hand, qualitative content analysis has a humanist orientation rather than a positivist one, thus it does not make use of statistics to analyse data, nor is it focused on making replicable inferences from texts (White & Marsh, 2006). Qualitative content analysis is anchored in approaches that involve interpretation of data into new emancipatory and critical narratives (Krippendorff, 2004).

Emancipatory and critical narrative approaches are aligned with a relativist position, rather than one single truth usually sought by positivist methods (Burr, 2015). This epistemological orientation was important for this systematic review, as it sought the

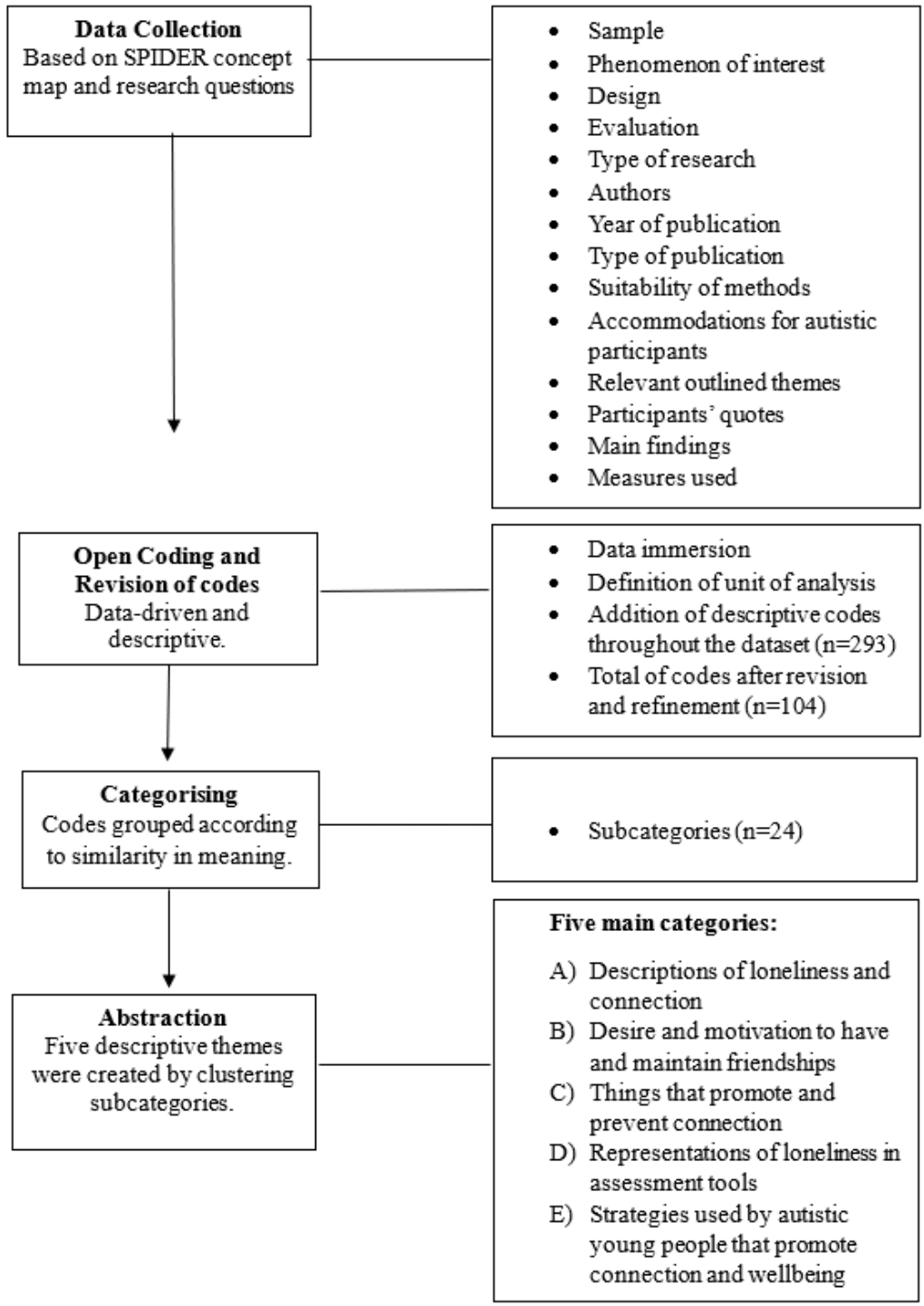
exploration of emergent concepts of loneliness that diverge from known, established perspectives. The study required approaches and methodologies that would foster the acceptance of alternative views of loneliness rather than an objective quantifiable answer (Burr, 2015). Therefore, adopting a humanist methodology for the synthesis, such as qualitative content analysis, aligned with the ontological and epistemological orientations of the thesis, which were detailed in Chapter Two.

As previously discussed, the sample of included studies in this systematic review was characterised by heterogeneity, including differing epistemological and ontological stances. Views that constitute study findings seldom come from researchers, but other times they come from parents or teachers, or from autistic young people. Even when compared within the same category, titles differ in context, sampling technique, design, methods, and measures. Qualitative content analysis is a flexible and content-sensitive method of analysis (Elo & Kyngäs, 2008) making it suitable to the complexity and diversity of this sample. Categories can be built by carefully comparing similarities and differences between data (Kyngäs et al., 2020) ultimately providing meaningful descriptions of what is known so far about the experiences of loneliness for autistic young people.

This review followed the guidance for conducting qualitative content analysis that suggests dividing the analytical process into three phases: preparation, organising and reporting (Elo & Kyngäs, 2008). Figure 2 shows a flowchart of the analytical process.

Figure 2

Flowchart of the Analytical Process



The preparation phase consisted of immersion in the dataset by reading it several times and by considering what would constitute a unit of analysis (Fingeld-Connett, 2014). Units of analysis are portions of data that are labelled (or coded) and can later be retrieved and grouped for further analysis (Joffe & Yardley, 2004). Deciding what constitutes a unit of analysis includes considering the length of each segment and how meaning can be extracted from them. If segments are too short, there is a risk of generating shallow and deconstructed findings and if segments are too long, there is the danger of generating abstract understandings of the dataset (Fingeld-Connett, 2014). For this systematic review, full sentences and paragraphs were considered ideal to generate nuanced and meaningful coding that would allow a thorough description of the contents.

The organising phase included open coding, revision, categorization and abstraction. The objective of coding is to capture the essence of a portion of data in one word or short phrase (Saldaña, 2021), creating concepts that will help to classify and understand the subject under investigation (Joffe & Yardley, 2004). An inductive approach was used as this is best suited for topics that have not been previously explored or when prior knowledge of a topic is fragmented (Kyngäs et al., 2020). Working inductively involves a bottom-up approach where new knowledge is data-driven, rather than theory driven (Thomas, 2006).

The coding process started with open coding, which was the addition of headings and notes describing units of analysis (Elo & Kyngäs, 2008). Table 5 shows an example of how open coding was conducted.

Table 5

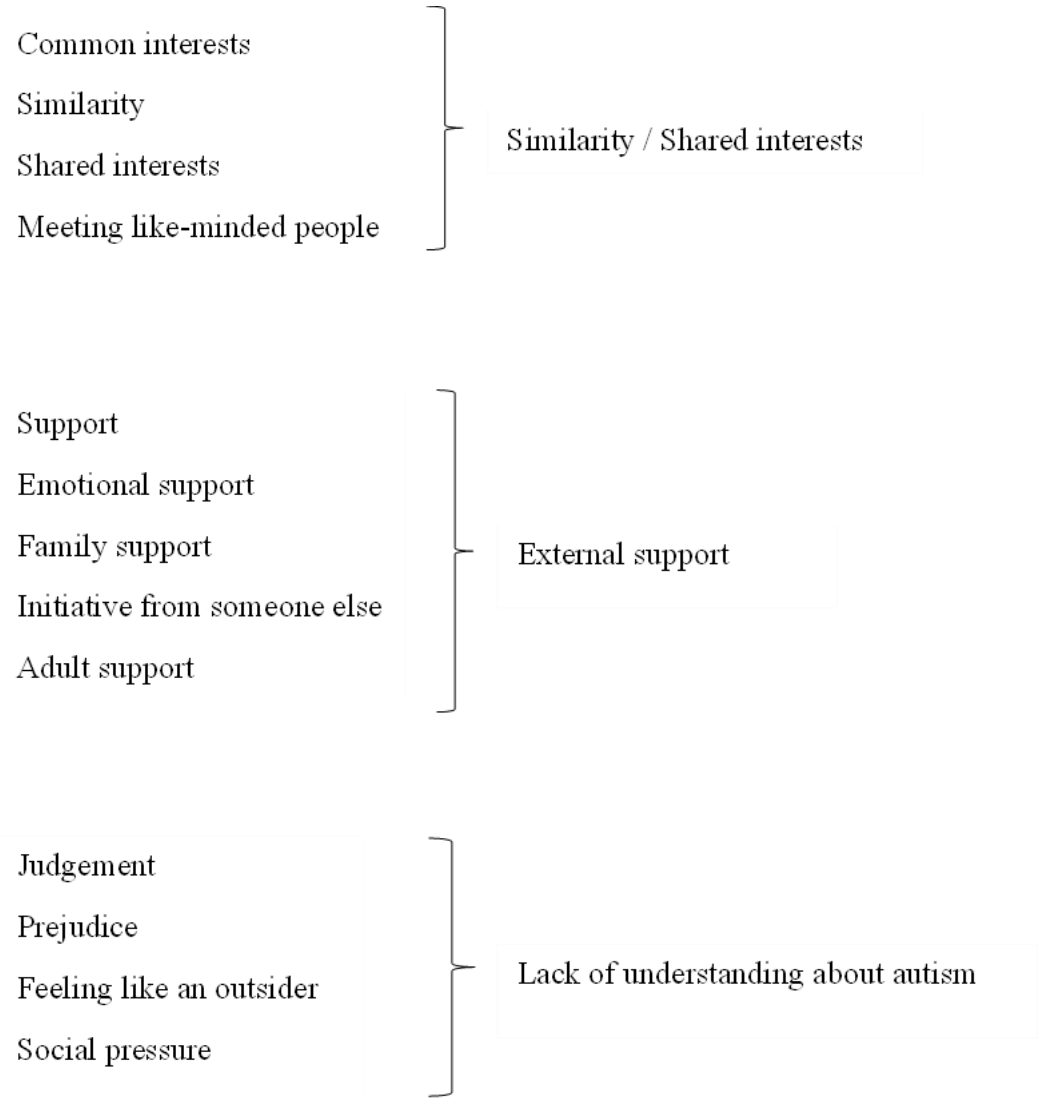
Example of How Open Coding Was Conducted

Title	Extracted data	Coding
O'Hagan & Hebron, 2017	The meaning of friendship: "Well I suppose friendship means like trust and respect. Like, I go up to a friend and sometimes I'll say something like that I've lost something, and they could say: 'Right well go to lost property.' Most of the time they will help me out." (p.12)	Friendship is based on trust. Friendship is based on respect. Friendship involves help and support.
	The students in this study did not mention intimate features of friendship such as sharing secrets; they tended to focus more on companionship and helping one another, supporting findings in previous quantitative studies.	Intimacy is not needed for connection.
	Parents' view: The students' lack of discussion of intimacy as a defining feature of friendship may also go towards explaining why, despite describing features of friendship, the students' parents and teachers felt that they did not have a fully developed understanding of friendship, as Max's father highlighted: "I don't think he truly knows what the word friendship is. Like, I have friend from childhood and that's what I would call proper friendship." All of the parents interviewed reported that their sons did not perceive friendship in the same way as them.	Parents' and teachers' views: Adolescents lack understanding of friendship. Different perception of friendship.

The objective of open coding was to reduce the original data, summarising key meanings that were relevant to answering the research questions (Schreier, 2012). This round of open coding generated 293 codes. Next, codes were transferred to a spreadsheet to be revised and reorganised (Mayring, 2014). Some were collapsed into one single code due to similarity; others were refined to better describe the intended meaning, and some were excluded. This revision reduced the initial codes to 104 codes. Figure 3 shows examples of how open codes were revised and reorganised.

Figure 3

Example of Revision of Open Coding



A common feature of content analysis is to calculate the frequency of codes present in the dataset. Counting frequency of words or codes is a tool to identify patterns and to understand how terms are used in a certain context (Hsieh & Shannon, 2005). However, in qualitative approaches, this kind of summative analysis can be limited if done on its own. Reducing the analytical process to quantification of frequencies, where high-frequency terms and codes are retained and low-frequency ones are dismissed, might exclude important meanings from the analysis. Kracauer (1952) explains that sometimes, an important part of

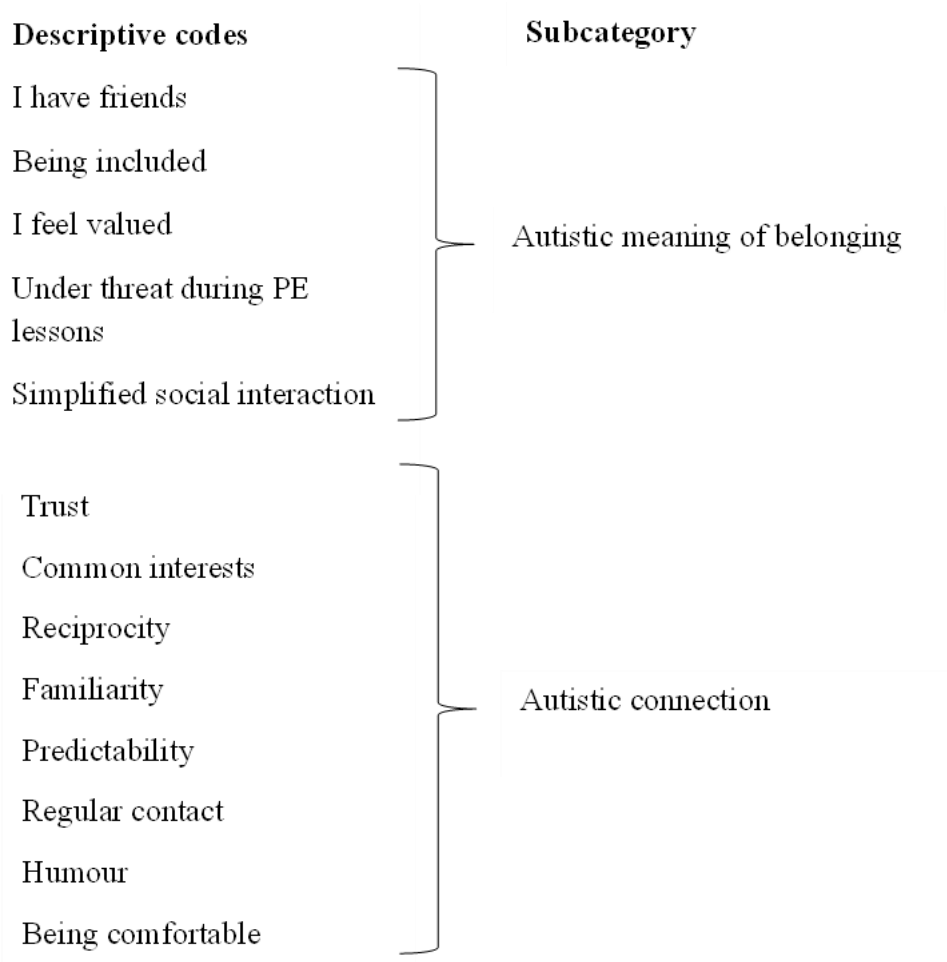
evidence might appear only once or rarely, which should not be a reason for being excluded from the analysis. For this systematic review codes were rated as high-frequency or low-frequency to identify possible patterns and to explore the most common use of language related to connection, belonging, isolation, exclusion and loneliness. However, although frequency was considered during the analysis, it did not determine the relevance or importance of a code, in line with Kracauer's (1952) position that infrequent occurrences may still hold significant analytical value.

Following this initial consideration of frequency, codes were then reviewed in relation to their relevance to the research questions. If central to answering a question, they were retained, if not they were excluded. An example of this is the code 'disclosure for acceptance', which appeared only once and could not be collapsed or connected to any other code or category. The code describes how an autistic young person felt more accepted by disclosing their diagnosis. This was not central to any of the research questions and due to its low frequency in this dataset, it also meant it might have been an isolated perspective. On the other hand, the code 'stigma' appeared twice and although low frequency, it was retained as it was considered useful to understanding experiences of connection.

Once the codes were revised and refined, they were organised in groups by being contrasted and combined (Kyngäs et al., 2020). Categorisation of codes involved going back and forth in the analysis (Lindgren et al., 2020). For this systematic review, this phase meant moving codes around many times, creating and extinguishing sub-categories, and thinking how clustered codes represented the concepts within the dataset. Figure 4 shows two examples of how codes were categorised.

Figure 4

Examples of How Codes Were Categorised



Abstraction is the last step in qualitative content analysis and it consists of creating main categories that describe the dataset by combining subcategories (Elo & Kyngäs, 2008) For example, the subcategories 'Lack of emotional and behavioural regulation', 'Unable to initiate', 'Issues with communication', 'Lack of understanding of relationships' and 'Not knowing what to say' were grouped under the main category 'Things that promote and prevent connection'. The analysis yielded five main categories that helped describe the dataset and answer the research questions: a) Descriptions of loneliness and connection; b) Desire and motivation to have and maintain friendships; c) Things that promote and prevent connection;

d) Representations of loneliness in assessment tools; and e) Strategies used by autistic young people that promote connection and wellbeing.

Results

Study Characteristics

The first searches resulted in 41 included studies (Table 6). Update searches resulted in an additional four studies (Table 7). Research was conducted in 12 countries, the majority in the USA (n=21), followed by the UK (n=9), Australia (n=4), Japan (n=3), and Belgium, Canada, China, Denmark, Germany, Ireland, Israel and Italy, with one study each. There were 2240 participants overall, with 1028 being autistic young people (all with a formal diagnosis of autism). Out of these, 703 were reported to be males, 202 females, one participant with gender fluid identity and 122 did not have their gender specified. Other participants were non-autistic young people (n=886), participants with motor and/or sensory disabilities (n=50), participants who identified as disabled (n=8) and participants with other neurodevelopmental disabilities (n=36). There were 178 family members reported as mothers (n=35), fathers (n=9), caregivers (n=7) and parents (n=127). There were 53 members of staff, including mentors (n=7), teachers (n=23), teaching assistants (n=7), learning support assistants (n=5), senior members of staff (n=1), support worker (n=1), head of resource provision (n=1), mental health professional (n=1), production assistant (n=1), self-employed artists (n=2) and volunteering students (n=2). Two members of staff did not disclose their position.

Most studies represented autistic young people attending mainstream schools (n= 11), followed by mainstream schools with support services for children with special educational needs (n= 8), outpatient clinics and other groups dedicated to developing skills or offering activities specifically for autistic people (n= 8), online and in-person support groups (n=3),

special schools or units (n= 4), research participants (n=5) and therapy clients (n=2). Two studies (Bauminger et al., 2003; Danker et al., 2019) recruited participants from more than on setting. One study used previously collected data (Dean et al., 2023) and one study recruited participants from institutes which were part of the primary author's network (Sumiya & Senjo, 2023).

Most qualitative studies provided descriptions of connection and belonging from the perspectives of autistic young people, with exploration of friendship development, social experiences, the understanding of belonging, how connection happens, peer relations and wellbeing. Half of the 24 qualitative studies asked autistic young people about their perceptions of these phenomena and half presented the perspectives of multiple stakeholders collectively. Therefore, the personal perspectives of autistic young people could be well represented in the analysis.

Table 6

Summary of the 41 Studies First Included in the Systematic Review

Author	Country of publication	Research design	Participants		Age range	Contexts	Quality assessment	Descriptions of Loneliness / Exclusion	Descriptions of connection and belonging	Personal Autistic-led strategies	Measures of loneliness
			Autistic participants	Other stakeholders							
Adamo, 2011	Italy	Psychotherapy report	1 m		14 years	Therapy client	n/a			✓	
Acker et al., 2018	UK	QL; Ph	14 m		13-18 years	Local support groups for autism	**		✓		
Ashburner et al., 2017	Australia	QL; CA	11 (8 m; 3 f)	12 Family members (3 m, 9 f) 7 mentors (6 m; 1 f)	17-21 years	Participants of Studio G (mentorship programme)	***		✓		
Bauminger et al., 2003	Israel	QT	17 (15 m, 2 f)	17 (15 m; 2 f)	8-17 years	Special education department and mainstream schools	***				✓
Berns, 2016	USA	PhD Thesis; QL; MCS	10 m		13-19 years	Participants from previous studies	***	✓	✓		✓
Bohnert et al, 2019	USA	QT	127 (103 m; 24 f)	127 parents/caregivers (gns)	12-17 years	Online support groups Advocacy group and clinics	***				✓
Bossaert et al., 2012	Belgium	QT	108 (SEN) 58 autistic (m)	108 m	12-13 years	Mainstream schools with SEN	***				✓
Bradley, 2016	UK	MM	12 (8 m; 4 f)	36 (24 m; 12 f)	11-12 years	Mainstream schools	**				✓

Author	Country of publication	Research design	Participants		Age range	Contexts	Quality assessment	Descriptions of Loneliness / Exclusion	Descriptions of connection and belonging	Personal Autistic-led strategies	Measures of loneliness
			Autistic participants	Other stakeholders							
Cage et al., 2016	UK	QL; TA	12 (11 m; 1 f)	5 school staff (gns)	12-15 years	Mainstream school	***		✓		
Chang et al., 2019	China	QT	101 (84 m; 17 f)	101 (53 m; 48 f)	10-19 years	Mainstream school	***				✓
Collier, 2018	USA	PhD Thesis; MM	8 m		13-18 years	Participants of Camp Jigsaw	**		✓		
Daniel & Billingsley, 2010	USA	QL; IPA	7 m		7-14 years	Mainstream school with special education support	***		✓		
Danker et al., 2019	Australia	QL; GT		20 high-school teachers (8 m; 12 f)		Mainstream schools and support units	**		✓		
De Gennaro, 2015	USA	PhD Thesis; QT	17 (14 m; 3 f)	25 (17 m; 8 f)	Mean = 14.58 (A) Mean = 13 (TD)	Private school for speech and language therapy; Local centres with services for autistic people.	**				✓
Feldhaus et al., 2015	Germany	QT	43 m		15-27 years	Autism therapy centre	***				✓
Foggo & Webster, 2017	Australia	QL; Ph	7 f		13-17 years	Mainstream school	***		✓		
Gallup et al., 2016	USA	QL; Ph	3 m		16-21 years	Adolescents who play games and are enrolled in mainstream schools	***		✓		
Glew, 2020	UK	PhD Thesis; QL; TA	10 (5 m; 5 f)	7 staff; 13 parents (gns)	11-14 years	Individuals participating	***		✓		

Author	Country of publication	Research design	Participants		Age range	Contexts	Quality assessment	Descriptions of Loneliness / Exclusion	Descriptions of connection and belonging	Personal Autistic-led strategies	Measures of loneliness
			Autistic participants	Other stakeholders							
						in drama project (Turtle Opera)					
Goodall & MacKenzie, 2019	UK	QL; TA	2 f		16-17 years	Special school	***	✓			
Haegele & Maher, 2022	USA	QL; TA	8 m		13-18 years	Mainstream school	***	✓	✓		
Hall, 2011	USA	PhD Thesis; QL; MCS	5 (3 m; 2 f)	Parents, teachers, special educators, support personnel and school psychologist (gns)	16-18 years	Mainstream school with autism support services	**		✓		
Hall, 2021	Canada	PhD Thesis; QL; GT	19 (13 m; 6 f)		13-16 years	Mainstream school	***		✓		
Halsall et al., 2021	UK	QL; TA	8 f	8 Parents 8 educators (gns)	12-15 years	Resource base attached to mainstream school	***			✓	
Howard et al., 2006	USA	QL; GT	1 m	1 parent (mother)	12y8m	Social skills group	***		✓		
Hurlbutt & LaPlante, 2010	USA	QL; CS		3 Parents and 3 teachers of 3 students in junior high (gns)	12-15 years	Mainstream school	***		✓		
Kunz, 2009	USA	PhD Thesis; QL; GT	7 (6 m; 1 f)	7 corresponding caregivers (gns)	15-19 years	Therapy clients from the University of Illinois	**		✓		
Lasgaard, et al., 2009	Denmark	QT	39 m	199 m	13-16 years	Special education school and	***				✓

Author	Country of publication	Research design	Participants		Age range	Contexts	Quality assessment	Descriptions of Loneliness / Exclusion	Descriptions of connection and belonging	Personal Autistic-led strategies	Measures of loneliness
			Autistic participants	Other stakeholders							
						mainstream schools					
Locke et al., 2010	USA	MM	7 (4 m; 3 f)	13 (gns)	Mean = 14.71 (A) Mean = 14.2 (TD)	Mainstream school with an autism spectrum programme	*				✓
Murphy et al., 2017	UK	QL; TA	8 (6 m; 2 f)		13-18 years	Mainstream schools	***		✓		
Myles et al., 2019	UK	QL; TA	8 f		12-17 years	Mainstream schools	**	✓	✓		
Nomura et al., 2012	Japan	QT	15 (lower elementary) 16 (higher elementary) 14 (Junior high) (gns)	89 (lower elementary) 87 (higher elementary) 105 (Junior high) (gns)		Mainstream schools	**				✓
O'Hagan & Hebron, 2017	UK	QL; CS	3 m	3 parents (2 mothers) + 1 key adult that worked with each student (gns)	13-15 years	Mainstream school with special ASC provision	**		✓		
Reynolds, 2017	USA	PhD Thesis; MM	34 (26 m;8 f)		14-17 years	Mainstream with special education services	***		✓		
Rossetti, 2007	USA	PhD Thesis; QL; ETH	1 m	9 f (non-disabled); 2 f (autistic older than 18); 1 m (Menkes syndrome); 1 f (physical disabilities); 2 f (learning disabilities); 2 f	17 years	Mainstream with special education services	***		✓		

Author	Country of publication	Research design	Participants		Age range	Contexts	Quality assessment	Descriptions of Loneliness / Exclusion	Descriptions of connection and belonging	Personal Autistic-led strategies	Measures of loneliness
			Autistic participants	Other stakeholders							
				(intellectual disabilities)							
Ryan et al., 2020	Ireland	QL; TA	10 f		12-15 years	Community service for children with ASD	***		✓		
Storch et al., 2012	USA	QT	60 (48 m; 22 f)		11-14 years	Participants enrolled in a psychosocial treatment study for anxiety	***				✓
Sumiya et al., 2018	Japan	QL; TA	11 (8 m; 3 f)		10-15 years	Private remedial centres College-based remedial centres Special education classes	***	✓	✓		
Watkins, 2016	USA	PhD Thesis; QL; CS	6 (5 m; 1 f)	5 parents (4 mothers)	17-23 years	Support group for parents of children with special needs; social media; Parent bulletin boards in schools.	***		✓		
Wendler, 2018	USA	PhD Thesis; QT	21 (4 m; 6 f; 1 gf)	Participants' parents (gns)	Mean = 15 years	Individuals enrolled in improv theatre classes.	**				✓
White & Roberson-Nay, 2009	USA	QT	20 (18 m; 2 f)		7-14 years	Outpatient clinic	***				✓

Author	Country of publication	Research design	Participants		Age range	Contexts	Quality assessment	Descriptions of Loneliness / Exclusion	Descriptions of connection and belonging	Personal Autistic-led strategies	Measures of loneliness
			Autistic participants	Other stakeholders							
					(Mean = 12.08)						
Whitehouse et al., 2009	Australia	QT	35 (28 m; 7 f)	35 (29 m; 6 f)	Mean = 14 years	Mainstream school	***				✓

QL = Qualitative; QT = Quantitative; Ph = Phenomenology; CA = Content analysis; GT = Grounded theory; IPA = Interpretative phenomenological analysis; TA = Thematic analysis; CS = Case study; MCS = Multiple case study; ETH = Ethnography; MM = Mixed Methods; m = male; f = female; gf = gender fluid identity; gns = gender not specified; SEN = (Special Educational Needs);

*** = excellent quality; ** = moderate quality; * = fair quality

Table 7

Summary of Four Studies Included After Update Searches

Author	Country of publication	Research design	Participants		Age range	Contexts	Quality assessment	Descriptions of Loneliness	Descriptions of connection and belonging	Personal Autistic-led strategies	Measures of loneliness
			Autistic participants	Other stakeholders							
Dean et al., 2023	USA	MM	58 (29m; 29f)		6-18 years	Previously collected data	***			✓	✓
Gerber et al., 2023	USA	QT; L	51 (41m; 10f)	25 non-autistics (11m; 14f)	8-17 years	Existing participant pool	***				✓
Schiltz et al., 2024	USA	QT; L	77 gns	36 (other NDD; gns)	9-25 years	Previous research participants	***			✓	✓
Sumiya & Senju, 2023	Japan	QT	16 (10m; 6f)	25 non-autistics (14m; 11f)	10-15 years	Institutes part of researcher network	***				✓

QT = Quantitative; L = Longitudinal; MM = Mixed Methods; m = male; f = female; gf = gender fluid identity; gns = gender not specified; NDD = neurodevelopmental disorder; *** = excellent quality; ** = moderate quality; * = fair quality.

Data Synthesis

Based on the qualitative content analysis five main categories were created. They summarise the dataset and answer the research questions: 1) descriptions of loneliness and connection; 2) desire and motivations to have and maintain friendships; 3) things that promote and prevent connection; 4) representations of loneliness in assessment tools; and 5) strategies used by autistic young people that promote connection and wellbeing.

1) Descriptions of Loneliness and Connection

Three studies gave descriptions of loneliness and isolation experienced by autistic young people, and one study (Berns, 2016) presented experiences of loneliness as one of its primary research topics.

Sumiya et al. (2018) explored emotions associated with friendships for autistic adolescents, who reported that loneliness was felt when they were excluded from activities or games: “When we were playing tag together, other students didn’t catch me, and they didn’t let me catch any one of them. I felt loneliness then,” (Sumiya et al., 2018, p. 7). Goodall and MacKenzie (2019) asked how autistic young girls experienced mainstream school and reported experiences of bullying, prejudice and social pressures, which contributed to feelings of loneliness. An absence of close friends, or people to relate to, being excluded from activities or from meeting up after school and not fitting in also contributed to feelings of loneliness. The following quotes illustrate these findings: “I found that I had no close friends I could talk to. I felt very lonely and often found myself without anyone to play with,” (Goodall & MacKenzie, 2019, p. 507). “I was isolated and separated, in like a bubble of depression and anxiety . . . but, I still felt the centre of attention with others looking at me and judging,” (Goodall & MacKenzie, 2019, p. 507). Haegele and Maher (2022) reported similar findings. In their study, feelings of belonging were largely unavailable during sports lessons

said to be imbued with typical conceptions of masculinity. Some autistic boys felt excluded from what was typically expected from them in this environment.

Berns (2016) provided an understanding of the experiences of friendship and loneliness for autistic boys. One participant defined loneliness as: “To feel like you don't have a place, to not really have people to be with, to just feel a longing for something, like someone to talk to…” (p.125). Another participant defined loneliness as a negative feeling: “It's kind of like being in a dark room. You can't see anything, and well, you don't know what's there, and you don't know what to do… and then paranoia starts to kick in a little bit. It's not fun,” (p.126). Autistic young people in this study also mentioned the need for meaningful and genuine personal connections. They said that interacting with people whom they do not feel a legitimate connection with is almost as bad as not having anyone: “If you have no one who will talk to you (with) honest interest in what you're saying, then that's what I feel like it's lonely,” (p.126). Collectively, loneliness was described by autistic young people as a negative feeling that emerges from being excluded from social activities, and feelings of inadequacy (not ‘fitting in’).

Descriptions of belonging and connection were explored in seven studies (Berns, 2016; Bradley, 2016; Collier, 2018; Haegele and Maher, 2022; Hall, 2021; Halsall et al., 2021; Myles et al., 2019) and helped to address the question of how ‘not lonely’ might feel for autistic adolescents. Belonging was associated with having friends, being included, acknowledged, and valued. Belonging was reported to be supported by social acceptance and self-acceptance, when young people felt that they were understood, fitted in, did not feel like an outcast, and were with like-minded people. For example, autistic young people felt belonging in environments with simplified social interactions, such as friendships with peers in different age groups, which “enabled them to explore relationships in safe and controllable situations,” (Halsall et al., 2021, p. 2080). Friendships with pupils identified as having

Special Educational Needs (SEN) were also reported to be positive, with "reduced social interaction demands," (Halsall, et al., 2021, p.2080). A peer mentoring programme that recognised autistic young people's academic strengths and placed them as mentors was evaluated by autistic adolescents as a way of contributing to feelings of belonging: "It was good. Others don't normally like my ideas or listen to me in class, but they did in the group," (Bradley, 2016, p. 282). When in secure relationships with peers that provided emotional support and demonstrated empathy, young people said this companionship was a source of joy, happiness and entertainment. Such positive experiences entail autistic young people to be "vulnerable with their friends and then experience the positive feedback of having friends accept and understand them," (Hall, 2021, p.134). Therefore, acceptance, understanding, acknowledgement, emotional support, empathy, and inclusion, reportedly enabled autistic young people to contribute authentically, consequently reducing camouflaging and increasing wellbeing.

2) Desire and Motivation to Have and Maintain Friendships

Nine studies with qualitative designs (Acker et al., 2018; Cage et al., 2016; Gallup et al., 2016; Hall, 2011; Hall, 2021; Kunz, 2009; Murphy et al., 2017; Myles et al., 2019; O'Hagan & Hebron, 2017) stated that autistic young people desire social relationships. Autistic young people personally described friendships as being valuable to them (Hall, 2011; Hall, 2021) and expressed wanting to have other people to "hang out with," (Cage et al., 2016, p.17), or "with whom to hang out, play, and talk...actively engage in activities with or keep them entertained," (Hall, 2021, p. 104). Some young autistic people expressed a strong urge to make social connections, but also a worry that treasured relationships could be lost by "messing things up with people," (Acker et al., 2018). Friendships were described as an "antidote" to loneliness by some autistic young people (Murphy et al., 2017). However, a desire for friendships was variable across studies. Sumiya et al. (2018) reported that some

autistic young people in Japan showed low levels of motivation to make new friends or to deepen existing friendships and Kunz (2009) reported that although autistic young people seemed to want to have social connectedness, "none demonstrated overt anxiety or unhappiness regarding the fact that none had such a connection," (p.79). In addition, for some participants a motivation to have friends was not related to feelings of loneliness, but to social pressure (Berns, 2016). For these young people, making friends seemed to come from motivations to be seen as one of their peers, avoiding feeling shame or anxiety, or experiencing low self-esteem for being different:

> *I'm different, but I can still act normal. In elementary school and junior high, I didn't act normal that often, but I've been trying to act somewhat normal in high school, so, like you know, I just don't do like weird stunts and such, so, I kind of fit in a bit more, but I kind of don't. You can point me out, but I'm not like that blatantly, obviously guy-climbing-up-on-the-roof. (Berns, 2016, p.109)*

For some autistic young people motivation to make friends was said to be low because they have difficulties finding shared interests, or knowing what people might be like before seeking friendships:

> *When I look around, I don't really see anything about a person that makes me think, 'Yeah, I wanna be friends with that person.' It's just hard for me to identify any like… like what interests the person might have or anything, or what they might be like as a person that would make me think of wanting to be their friends or at least trying to be their friend. (Berns, 2016, p. 110)*

3) Things that Promote and Prevent Connection

i) Authenticity: Being Yourself Without Negative Judgment

Authenticity was discussed by autistic young people in four studies as something that is needed to feel meaningfully connected (Foggo & Webster, 2017; Gallup et al., 2016; Hall,

2021; Murphy et al., 2017). When discussing aspects of friendships that they valued, some young people cited "understanding, respect, honesty and the ability to be themselves without judgement," (Foggo & Webster, 2017, p. 79), or being accepted for who they are:

> *I'm friends with the, with a bunch of different people that have many different personalities from like one friend to a different friend. And yeah it's just a matter of me being myself around other people and they accept me for who I am even though they have different personalities I still get along with them (Hall, 2021, p. 102).*

Self-esteem and self-confidence were briefly discussed as contributing to connection with peers, as "these qualities are likely to empower students to initiate conversations with their peers," (Danker et al., 2019, p. 2929). This same study also explored how building a positive self-image can be challenging for some autistic adolescents because they sometimes struggle with their own perception of how different they are from their peers. A teacher shared: "Matt is not very comfortable with the fact that he's different and that he has additional needs, and that we support him. He's started to pull away a little bit," (pp. 2929-2930).

Some autistic traits such as sensory issues, repetitive behaviours, the diagnostic label, and behaviours used to manage emotions, were also voiced by participants as hindrances that make connection more difficult (Berns, 2016; Danker et al., 2019; Hall, 2021; Rossetti, 2007). Embarrassment due to rejection, fear of humiliation, fear of attracting negative attention, fear of judgement, not being accepted or liked, and other negative feelings such as finding themselves different or strange can stop autistic young people from trying to connect to other people (Acker et al., 2018; Bradley, 2016; Danker et al., 2019; Kunz, 2009; Hall, 2011; Hall, 2021; Myles et al., 2019; Ryan et al., 2021). Less frequently mentioned were difficulty of letting go of their own routine (Hall, 2021), immaturity, lack of Theory of Mind

(Berns, 2016) and shyness (Ryan et al., 2021). Some parents of autistic children believed that the barriers that keep their children from connecting meaningfully to others are their lack of social skills, their obsession with one topic, the absence of emotional ties and prevalence of shallow contact (Kunz, 2009).

ii) Safe Spaces, Trust, and Reciprocity

Eleven studies (Ashburner et al., 2018; Daniel & Billingsley, 2010; Foggo & Webster, 2017; Gallup et al., 2016; Glew, 2020; Hall, 2021; Hurlbutt & LaPlante, 2010; Murphy et al., 2017; Myles et al., 2019; Reynolds, 2017; Ryan et al., 2021) reported safe environments as being a fundamental requirement for connection. A safe environment was explained by participants to be a space that is free from bullying or judgement: "I feel safe and not threatened, like when I see a movie and I write about it, and friends don't say mean things about my choices," (Watkins, 2016, p.111). Associated with safe spaces were trust and reciprocity (Adamo, 2004; Daniel & Billingsley, 2010; Foggo & Webster, 2017; Glew, 2020; Hall, 2021; Howard et al., 2006; Murphy et al., 2017; O'Hagan & Hebron, 2017; Reynolds, 2017; Ryan et al., 2021). Reciprocity was frequently linked to common interests by autistic young people, who said that spending time with like-minded people who enjoy the same things as they do, was a step towards feeling connected (Ashburner et al., 2018; Berns, 2016; Collier, 2018; Daniel & Billingsley, 2010; Haegele & Maher, 2022; Hall, 2021; Howard et al., 2006; Murphy et al., 2017; Reynolds, 2017): "It's nice to have friends who understand what I'm going through for once," (Glew, 2020, p. 28).

Individual characteristics were frequently mentioned by participants as reasons for being excluded, bullied, teased, or isolated by peers. Being hyperactive, inattentive, overstimulated or being physically agitated were some examples given by Hall (2021). Difficulties with emotion and behaviour regulation (Collier, 2018; Hall, 2021), initiating social contact (Berns, 2016; Murphy et al., 2017; Rossetti, 2007), and communication during

social situations (Berns, 2016; Danker et al., 2019; Hall, 2011; Hall, 2021; Hurlbutt & LaPlante, 2010; Myles et al., 2019; O'Hagan & Hebron, 2017) were all described as barriers to connection. These included difficulties understanding relationships and uncertainty about what to say in social interactions.

Social barriers that prevented connection and were frequently mentioned by autistic young people included receiving different treatment, being bullied, ignored, and judged (Acker et al., 2018; Gallup et al., 2016; Goodall & MacKenzie, 2019; Haegele & Maher, 2022; Hall, 2011; Hall, 2021; Myles et al., 2019; Reynolds, 2017; Watkins, 2016). Social pressure was felt by autistic young people when they had difficulty fitting in and by the prevalence of face-to-face interactions (Collier, 2018; Hall, 2011; Hurlbutt & LaPlante, 2010). The lack of inclusive practices and accommodations to autistic needs, also seen as lack of support, was said to result in situations being unpredictable, which can be difficult for autistic young people to deal with (Danker et al., 2019; Myles et al., 2019).

Occasionally, the ambiguity of social interactions (Acker et al., 2018), parents' negative attitudes towards disability (Danker et al., 2019), fast pace of changes (Haegele & Maher, 2022), lack of realistic expectations (Danker et al., 2019), misinterpretation of behaviours and speed of interactions (Rossetti, 2007) were reported as connection inhibitors.

iii) Familiar People and Familiar Places

Familiarity with people was described by autistic young people as getting to "know each other a lot" and "becoming a lot closer," (Hall, 2021, p. 105). Familiarity was said to help with the predictability of interactions and to facilitate engagement with peers (Glew, 2020; Hall, 2011; Hall, 2021). It "reduced the degree of risk and discomfort associated with social interaction," (Hall, 2021, p. 143). Feeling in control of interactions such as through creating imaginary friends (Adamo, 2004) or choosing to have online interactions (Gallup, et al., 2016) was described as helping autistic young people avoid feelings of dependence and

vulnerability. Keeping regular contact with friends, being kind and honest with each other and sharing humour, were each described by autistic adolescents as fostering connection (Adamo, 2004; Foggo & Webster, 2017; Hall, 2021; Howard et al., 2006; Murphy et al., 2017; Reynolds, 2017; Rossetti, 2007).

iv) Supported Activities.

Seven studies (Berns, 2016; Cage et al., 2016; Danker et al., 2019; Foggo & Webster, 2017; Hall, 2021; Myles et al., 2019; O'Hagan & Hebron, 2017) mentioned emotional and practical supports as tools to foster connection. Three studies (Daniel & Billingsley, 2010; Howard et al., 2006; Rossetti, 2007) recognised family involvement as being valuable to promoting connection, whereby friendships develop from family acquaintances. Ashburner et al. (2018) found that interactions guided by adults such as mentorships can be helpful to promote connection. Rossetti (2007) also mentioned that modelling of social behaviours was appreciated by one young person in their study:

> *I am thinking it's so pleased that people only can have the greatest feelings of security where the teachers are having the intelligence to be a bridge that can cross over the distances of inconsolation of the sad feelings…I think it's so difficult to initiate conversation questions if you don't have a teacher in the introduction. I look to an adult to really make the bridge (pp. 170-171)*

Glew (2020) and O'Hagan and Hebron (2017) suggested that structured activities, where autistic adolescents are offered opportunities to socialise and the social initiation is led by someone else, can be positive to support connection. Additionally, Hurlbutt and LaPlante (2010) and Rossetti (2007) said that sharing understanding about autism works as an indirect tool that contributes to feelings of connection. Participants in four studies (Danker et. al., 2019; Glew, 2020; Rossetti, 2007; Watkins, 2016) said that creating inclusive environments

could mean changing the pace of social interactions to allow gradual participation of young autistic people in schools (Glew, 2020). This includes allowing extra time during supported social interactions to aid different communication styles (Rossetti, 2007). Less frequently discussed were ways to support communication in non-verbal ways, such as creating environments where verbal communication is not imperative (Myles et al., 2019) or by "becoming adept with subtle, non-spoken prompts" that could help young autistic people during social interactions (Rossetti, 2007, p.194).

4) Representations of Loneliness in Assessment Tools

Loneliness was predominantly measured quantitatively using standardised loneliness scales. The most used questionnaire was the Loneliness Rating Scale (Asher et al., 1984), used in its original form by four studies (Bohnert et al, 2019, Bradley, 2016; Dean et al., 2023; Locke et al., 2010). The Loneliness Rating Scale is a 24-item scale completed by children aged eight to 12 years old to assess feelings of loneliness and social dissatisfaction (Asher et al., 1984). Adaptations of this scale were used by another six studies as follows: Bauminger et al. (2003) retained the original 24 items of the questionnaire and added six additional loneliness items to the scale, which explored the emotional and social aspects of loneliness, based on previous research with autistic individuals. For example, "I feel very sad in class" and "I feel bored during most of the free time in school" (Bauminger et al., 2003). This same modified version was used by Sumiya and Senju (2023) and by White and Roberson-Nay (2009). Nomura et al. (2012) used a version of the Loneliness Rating Scale developed by Maeda (1995) to investigate loneliness and characteristics of social behaviour in peer-rejected children. Storch et al. (2012) used only 16 of the 24 original items related to loneliness and left the eight filler items out in their adaptation of the measure.

The second most used measure of loneliness was the third version of the UCLA Loneliness Scale (Russell, 1996). Six studies used versions of this measure, with De Gennaro

(2015), Gerber et al. (2023) and Lasgaard et al. (2009) using the original scale with its 20 items. Chang et al. (2019) used a Chinese version, which contained eight items. Feldhaus et al. (2015) used a German version containing 20 items and Wendler (2018) used three items of the original scale.

Six out of the 12 items of the Loneliness and Aloneness Scale for Children and Adolescents (LACA) developed by Marcoen et al. (1987) were used by Bossaert et al. (2012). Whitehouse et al. (2009) opted for the original de Jong-Gierveld Loneliness Scale (de Jong-Gierveld and Kamphuis, 1985) which is a self-report questionnaire. Berns (2016) used the Peer Network and Dyadic Loneliness Scale (PNDLS, Hoza et al., 2000). Finally, Schiltz et al. (2024) also used modules three and four of the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000; 2012) as measures of loneliness.

Five studies considered the suitability of the measuring tools being used. Berns (2016) stated that the PNDL scale had not yet been used to investigate experiences of loneliness for autistic adolescents, however, the measure was used with the developers' permission. Schiltz et al. (2024) acknowledged limitation of the ADOS as a metric of loneliness. They also commented on the lack of psychometric validity of the revised Asher Loneliness Scale's for autistic people. Bauminger et al. (2003) adapted the Loneliness Scale (Asher et al., 1984) adding six items based on previous research with autistic children and Sumiya and Senju (2023) and White and Roberson-Nay (2009) chose to use this altered version in their research.

Ten studies compared the scores on loneliness scales for autistic and typically developing young people (Bauminger et al., 2003; Bossaert et al., 2012; Chang et al., 2019; De Gennaro, 2015; Feldhaus et al., 2015; Gerber et al., 2023; Lasgaard et al., 2009; Locke et al., 2010; Nomura et al., 2012; Whitehouse et al., 2009). In eight out of the ten studies,

autistic young people reported feeling lonelier than their peers. De Gennaro (2015) did not find a statistically significant difference in reports of loneliness in their sample. Gerber et al. (2023) also found no difference between autistic and no autistic self-reported loneliness at the beginning of their study, but a small statistically significant decrease in self-reported loneliness for autistic participants over the next six months. Schiltz et al., (2024) who compared autistic and non-autistic groups with other neurodevelopmental disabilities, found similar levels of loneliness between both groups.

For autistic young people, high anxiety (Bauminger et al., 2003) and higher ratings of social impairment and difficulties with emotional control (Bohnert et al., 2019) were associated with reports of loneliness. Storch et al. (2012) found that nearly half of their sample of 60 (48 males) autistic adolescents reported high levels of loneliness. In Wendler's (2018) study, autistic adolescents with increased social difficulties reported increased loneliness, whereas autistic individuals with growth mindset reported less loneliness. Both Schiltz et al. (2024) and Sumiya and Senju (2023) found that feelings of loneliness increase with age for autistic young people and Sumiya and Senju (2023) identified that loneliness is mediated by companionship (one aspect of friendship). Dean et al. (2023) found a significant relationship between being mutually involved in a social activity and loneliness.

5) Personal Strategies That Promote Connection and Wellbeing

Strategies mentioned by autistic young people that allowed them to explore their identities and the dynamics of social interaction safely included: engaging with fictional characters by watching shows, videos on the internet or playing videogames (Berns, 2016); exploring alternative realities by creating "fantastical ideal universes" that can be joined with role-play, by engaging online or through comic books (Acker et al., 2018). "Drama, video or studying English Language to learn about the social world without directly interacting with it" (Acker et al., 2018, p. 15) were also mentioned. Some autistic young people created

imaginary friends to fulfil their need for companionship and intimacy (Adamo, 2004) or to explore and have control over relationships (Halsall et al., 2021). Spending time alone with personal interests (Goodall & MacKenzie, 2019; Hurlbutt & LaPlante, 2010), playing with pets (Berns, 2016), and mixing with younger children or with adults (Halsall, 2021, Hurlbutt & LaPlante, 2010) were also mentioned as strategies that promote wellbeing.

These strategies were discussed by autistic young people when asked about camouflaging (Halsall et al., 2021), their experiences of friendship and loneliness (Berns, 2016), their experiences of mainstream school (Goodall & MacKenzie, 2019), social issues surrounding autism (Hurlbutt & LaPlante, 2010), their experiences of anxiety (Acker et al., 2018) and as part of a therapeutic process (Adamo, 2004). Researchers' evaluations of these strategies were mixed. Imaginary friends, for example, were described by Adamo (2004) as a "constant dilemma" in the therapy room. Although imaginary companions "performed a vital function," protecting the autistic person from "an unbearable sense of emptiness, unconnectedness and deadness," they also "interfered with the possibility of establishing relationships with alive human beings, and they had a quality of addictiveness," (p. 276). Similarly, Acker et al. (2018) highlighted the "possible detrimental effects" of imaginary friends or fantastical realities linked to special interests as they can "become obstacles to meaningful relationships," (p. 16). However, Acker et al. also expressed the importance of investigating the role of fantasy for autistic young people due to its potential promotion of wellbeing. One parent of an autistic young person (Halsall et al., 2021) described imaginary friends as a compensation for the lack of real friends: "I do wonder if those (imaginary) friends are because she doesn't have that many real friends," (p. 2080).

Finally, three studies highlighted strategies that contribute to wellbeing and do not require connection with other people. Hurlbutt and LaPlante (2010) described "spending time with own interests" as being "extremely important to the adolescent with AS," (p. 91) and

Goodall and MacKenzie (2019) described how one autistic young person "ranked having friends as the least important aspect for making school more enjoyable" as "she was happy spending time alone" (p. 508). Berns (2016) also said that engagement with animals or fictional characters as a strategy to promote wellbeing is a novel finding and investigation in this area should be extended.

Discussion

This systematic review described how loneliness and meaningful connections are experienced by autistic young people, as represented within academic literature.

An Overview of the Experiences of Loneliness for Autistic Young People

Loneliness has been reported to be more commonly experienced by autistic young people when compared with their non-autistic peers (Bauminger et al., 2003; Chang et al., 2019; Feldhaus et al., 2015; Laasgard et al., 2009; Locke et al., 2010). Loneliness has also been associated with higher anxiety (Bossaert et al., 2012; Chang et al., 2019; Nomura et al., 2012; Storch et al., 2012; Wendler, 2018; White & Roberson-Nay, 2009) and depressive symptoms (Whitehouse et al., 2009). However, loneliness has rarely been defined by autistic people, meaning these estimates must be interpreted with caution. This review demonstrated that measures of loneliness are predominantly based on a conceptualisation of loneliness that does not include autistic views and have been used with limited interrogation of their suitability. Consequently, assumptions represented within the reviewed literature limit experiences of connection and belonging for autistic young people mostly to social relationships, such as friendships with peers. These assumptions reflect a 'typical' way of understanding loneliness, characterised by 'normalised' views of being with other people (Hawkley & Cacioppo, 2010), failing to recognise legitimate autistic experiences (Milton, 2012; Whitehead, 2023). Whilst possibly unintended, this representation of what constitutes connection and belonging reinforces a historical trend of defining autism based on social

deficits (Milton et al., 2023). To truly understand and include autistic people in research literature, it is particularly important to challenge neurotypical frameworks that might determine what friendships or connection should look like (Rossetti, 2007).

Loneliness as experienced by autistic young people has not yet been investigated as a main topic of qualitative research. Qualitative designs analysed in this review offered discussions of loneliness as part of wider domains, such as friendship (Berns, 2016; Daniel & Billingsley, 2010; Gallup et al, 2016; Hall, 2011; Hall, 2021; Howard et al., 2006; O'Hagan & Hebron, 2017; Rossetti, 2007; Ryan et al., 2021; Sumiya et al., 2018), relationships (Murphy et al., 2017), social experiences (Foggo & Webster, 2017; Hurlbutt & LaPlante, 2010; Kunz, 2009; Myles et al., 2019), anxiety (Acker et al., 2018), wellbeing (Danker et al., 2019; Glew, 2020), belonging (Haegele & Maher, 2022), camouflaging (Halsall et al., 2021), mainstream education (Goodall & MacKenzie, 2019), concerns with reputation (Cage et al., 2016), post-school transition (Ashburner et al., 2018) and development of social skills (Watkins, 2016). There is a need for research that focuses specifically on autistic young people's experiences of loneliness.

The second main finding of this review is that a desire to have social relationships, or to be socially connected to peers, is not universal amongst autistic young people. Cacioppo and Patrick (2008) explain that for some people, the motivation to connect socially can emerge from feeling lonely. The same research reports that loneliness can feel threatening and make an individual feel vulnerable, without protection or assistance from others. Although this model rings true for some autistic young people, a more detailed analysis, aligned with the neurodiversity framework, might expand this perspective. As Berns (2016) raised, some autistic young people are moved to grow social relationships due to social pressure. Their efforts to be socially connected seem to stem from a desire to fit into governing social standards rather than promoting feelings of connection and wellbeing that

make personal sense. This can be a problematic strategy, as previous findings suggest that trying to conform to non-autistic social demands can lead to increased loneliness (Grace et al., 2022). In this review, friendships were shown to contribute to feelings of humiliation and rejection for some autistic young people, who worried about doing and saying the right things. Gerber et al. (2023), for example, discuss how the effects of the pandemic might have given autistic youth increased flexibility in their daily social interactions, reducing anxiety, peer-victimisation and consequently reducing self-reported loneliness.

Alternative ways of feeling 'not lonely' were described personally by autistic young people and did not always include peer relationships. Strategies such as engaging with fictional characters, alternative realities, interacting with pets or imaginary friends should be better investigated as personal strategies that promote wellbeing and are meaningful to autistic young people. Autistic people emphasised feeling acknowledged, included, and valued, with both social acceptance and self-acceptance, which might resonate with definitions of existential loneliness more than loneliness as defined by the number or quality of relationships with other people (Baek et al., 2023; McKenna-Plumley et al., 2023). It is, however, difficult to disentangle the meaningfulness of peer relationships from how accepting social contexts are.

The Importance of Inclusive Social Contexts and the Development of Meaningful Support

Social environments can contribute significantly to identity construction (Mesa & Hamilton, 2022a), the development of collective and personal self-esteem and psychological wellbeing (Cooper et al., 2017). This review has evidenced how social spaces enable autistic young people to connect socially with others when they choose to. To feel connected, accepted and socially satisfied, autistic young people said they needed reciprocity, trust, authenticity, and spaces free from bullying and judgement. The social model of disability emphasises such inclusive social contexts and the development of meaningful support, as it

situates the problems faced by disabled people within society's disabling barriers rather than focusing on individual deficits and impairments (Oliver, 2013). When adopting an approach that sees autism as a neuro-divergence, rather than a disorder, the environment becomes the focus of interventions. Instead of 'repairing' the individual, support comes as a social response to their needs, shaped by enabling environments where all individuals can thrive (Pellicano & den Houting, 2022; Sonuga-Barke, 2023). This review identified strategies to create inclusive social spaces and meaningful support as described by autistic young people. They consisted of environments with flexible practices such as adopting a slower pace for social interactions or considering communication preferences, which can help with interpersonal exchanges and can facilitate social engagement. For young autistic people who want to develop social relationships, structured activities led by adults or family members can support social engagement. Finally, wider understanding about autism can inform better practices in autism research, education and training, media representation and how social spaces are planned. As discussed by Turnock et al. (2022) these not only promote inclusion of autistic people but contribute to reduced stigma and the creation of social environments that are free from bullying and judgement.

Historically, autism has been medically and scientifically framed as a disorder (Donvan & Zucker, 2016), which has led to predominantly negative perceptions of autistic people and camouflaging of their autistic status (Botha et al., 2022). This context also contributes to self-stigma and internalised oppression (Milton, 2012). In this review, some autistic young people, parents and people who work with autistic young people mentioned individual differences, such as sensory sensitivities, behaviours used for self-regulation and different communication styles, as hindrances to establishing or maintaining social relationships. In creating inclusive environments, individual differences are not understood as barriers to be overcome by the autistic young person: "Differences in neurology may well

produce differences in sociality" (Milton, 2012, p. 886), which requires an ongoing interactive process for differences to be understood, accepted, and accommodated. Such environment might contribute to positive identity management, self- acceptance and authenticity, all cited by autistic young people, and recognised in personal accounts of autistic adults (Cook, 2018; Gadsby, 2022; Poe, 2020; Prahlad, 2017; Price, 2022), as important elements to foster connection.

Current Measuring Tools and Their Suitability for Autistic Adolescents

The studies with quantitative designs included in this review frequently relied on definitions that represent neurotypical ways of experiencing loneliness. Scales that have been consistently used to assess loneliness for autistic adolescents, were based on concepts of loneliness that do not include autistic views. There seems to be an assumption that loneliness is experienced similarly by autistic and non-autistic people. This conclusion is not supported by this review.

A closer look at individual items of existing loneliness scales reveals that some items may not appropriately reflect autistic young people's experiences of loneliness as summarised in this review. For example, the UCLA Loneliness Scale (Russell et al., 1980), developed in English for use with non-autistic young adults (Maes et al., 2022), implies that "having no one to talk to" and "doing things alone" are indicators of loneliness. However, some autistic young people describe spending time alone with their own interests as a positive and important experience (Berns, 2016; Goodall & MacKenzie, 2019; Hurlbutt & LaPlante, 2010). As another example, the Children's Loneliness and Social Dissatisfaction Scale (Asher et al., 1984), designed for use with children up to 12 years old presents items such as "It's hard for me to make friends" and "I don't have any friends," which limit experiences of feeling 'not lonely' to having social relationships. In this review, the reported desire of autistic young people for social connection varied across studies (Berns, 2016;

Kunz, 2009; Murphy et al., 2017; Sumiya et al., 2018) showing that not all autistic young people pursue social relationships. Similarly, the de Jong Gierveld Scale (de Jong-Gierveld & Kamphuis, 1985) and the LACA (Marcoen et al., 1987), have items where lack of friendships indicate loneliness, such as “I miss having a really close friend”, “I find my circle of friends and acquaintances too limited”, and “I think I have fewer friends than others”. Whilst some autistic adolescents describe loneliness as a negative feeling associated with exclusion from social activities (Sumiya et al., 2018), an absence of close friendships (Goodall & MacKenzie, 2019), or lacking people to talk to (Berns, 2016), other perspectives challenge this more conventional understanding of loneliness. These contrasting views raise concerns about the suitability of current measurement instruments used to understand experiences of loneliness among autistic young people.

Grace et al. (2022) in their systematic review of how loneliness has been conceptualised for autistic adults, offer a critique of how researchers have not fully examined the validity of measuring instruments, and when efforts have been made to develop measures, these have been without in-depth involvement of the autistic community. This review reported complementary findings: researchers frequently assume that definitions of wellbeing and its essential contributing factors are comparable for autistic and non-autistic people (Caruana et al., 2021; Cassidy et al., 2018a; Cassidy et al., 2018b; Milton et al., 2016). Autistic people have previously raised concerns over validity and risks of studies that use measuring tools that have not been validated with the autistic community (Nicolaidis et al., 2019).

In this review, three studies considered the suitability of the standardised measuring tools used. Although Bauminger et al. (2003) adapted the Loneliness Rating Scale (Asher et al., 1984) following research with autistic individuals, it would be beneficial, as cited by

Grace et al. (2022), to have included extensive consultation and collaboration with autistic people, like the work done by McConachie et al. (2018) in the field of quality of life.

A Revised Definition of Loneliness

Loneliness is a phenomenon that has been conceptualised, theorised, empirically investigated and therefore, redefined throughout the years (Cramer & Barry, 1999). The understanding of loneliness has evolved from a unidimensional (Russell et al., 1980) to a multifaceted conceptualisation (DiTommaso & Spinner, 1993; Schimidt & Semat, 1983; Weiss, 1973) that has produced measuring instruments based on specific dimensions of the construct. Much of the contemporary research on loneliness, and the consequent development of measuring instruments have been based on Weiss's (1973) influential dichotomous conceptualisation, that separates loneliness into two dimensions: social and emotional loneliness (MacEvoy et al., 2011). Another dimension that has been explored by scholars but overlooked in empirical work is existential loneliness (McKenna-Plumley et al., 2023), which is defined as "a feeling of being fundamentally separated from others and the world" (Bolmsjö et al., 2019, p. 1315). None of these dimensions, however, have been confirmed to be the same for autistic young people experiencing loneliness, suggesting the need for a revised definition of the construct from autistic perspectives.

An updated definition of loneliness should include subjective autistic experiences, and wide participation of the autistic community as full partners in research (Whitehead, 2023). This review has shown that many subjective autistic experiences related to how autistic young people feel connected (or not lonely) have not been fully explored by researchers. Autistic young people have described authentic forms of connection, such as engaging with fictional characters and alternative realities. These suggest meaningful wellbeing strategies, assumed to be inadequate within a neuronormative framework (McLean & Syed, 2016; Whitehead, 2023). A new conceptualisation of loneliness will have to consider these ways of

finding meaningful connection with appreciation of difference and autistic strengths, as foregrounded by the neurodiversity concept (Botha et al., 2022; Pellicano & de Houting, 2022).

To explore new perspectives and expand the conceptualisation of loneliness and connection, future research should focus on qualitative investigations with the use of creative and flexible methods of data collection, within a participatory research framework. Qualitative research is well suited to study complex phenomena (Stutterheim & Ratcliffe, 2021) and to offer better understanding of social and psychological processes (Willig, 2019), as it involves detailed exploration of the many threads of a given topic, paying close attention to context, culture, interpretation of findings, and ethical issues (Yardley, 2000). This approach would help researchers to go beyond the individual, broadening their investigation to include the interaction between context and individual factors that at times has disabling effects for autistic people (Pellicano & den Houting, 2022).

Using creative and flexible research methods to gather data and insights from autistic populations will enhance the quality of descriptive data and encourage autistic people to participate in research, by offering methods that can capture autistic narratives (Ridout, 2017), cultivate community engagement, promote agency and address power imbalances (Stutterheim & Ratcliffe, 2021). Suitability of traditional methods of inquiry should be examined, preferably in consultation with the autistic community, before being used to investigate autistic experiences (Nicolaidis et al., 2019). Research design that truly pursues the participants' voice will be flexible and account for communication preferences rather than expecting participants to engage with methods that have been informed by non-autistic people (Ridout, 2017). In addition, research that draws on lived experience has the potential to address issues that are more relevant to communities and has an impact on people's everyday lives (Pellicano & den Houting, 2022).

Finally, participatory methods are another important pillar for the development of impactful results in the field of loneliness and connection for autistic adolescents. Results of this review show that, although some authors made the effort to adapt data collection instruments and accommodate individual needs, further action is required to include autistic voice in research. Inviting the autistic community to co-produce is giving autistic people power to put their needs and insights before any non-autistic expectation (den Houting, 2021).

Limitations

Although a larger number of independent reviewers make for enhanced rigour (Gray et al., 2017), this study was limited as the initial phase of this PhD project. The main researcher (LLW) was guided by a small supervisory team who were actively involved throughout and had an independent rater (ET) for the first title, abstract and full-text screening.

The review included studies from many different countries; however, several populations worldwide have not been represented. There are no findings from South America, Africa, Eastern Europe, South or Southeast Asia. Only participants with verbal communication and no learning disabilities were recruited with one exception (Rossetti, 2007). Representativeness challenges have also been reported by other researchers doing systematic reviews that target autistic populations (Cook et al., 2021; Grace et al, 2022). This issue could partly be addressed by broadening the research scope and by developing methodologies that can capture autistic narratives (Whitehead, 2023).

Titles were limited to publications in English; therefore, relevant materials published in other languages will have been excluded. Loneliness was examined as part of broader domains; therefore, it is not possible to draw firm conclusions of how loneliness is felt by

autistic young people. Finally, as previously discussed, findings derived from studies that used standardised measures, which have not been designed nor validated by autistic people, should be treated with caution.

Bridging Section

Study One of this thesis was a systematic review of the literature on loneliness for autistic young people. The main findings highlighted a paucity of qualitative descriptions of loneliness from autistic young people's perspectives. The review also showed that loneliness has predominantly been conceptualised as a dissatisfaction with social relationships, which contradicts findings that suggest autistic young people may experience connection differently. In addition, much of the existing research has been based on non-autistic perceptions of loneliness and connection, accompanied by the use of measuring instruments that originated from these assumptions.

The results of this systematic review foregrounded emerging descriptions of meaningful connection for autistic young people. Based on the findings, routes for a reconceptualisation of loneliness were suggested, aligned with the ontological and epistemological orientations of the thesis. The findings of the systematic review opened two possibilities for further exploring experiences of loneliness for autistic young people. The first was to seek a redefinition of loneliness from autistic perspectives, using creative and flexible methods, with a strong participatory ethos. The second was to investigate how loneliness measurement scales might adapt with this new understanding. The next two chapters will explain in more detail how these two investigations were designed and conducted.

Chapter 4: A Participatory and Creative Exploration of How Autistic Young People Experience Loneliness

This chapter builds on the findings of the first study, which was a systematic review of the literature to find out what is already known about the experiences of loneliness for autistic young people. The purpose of this chapter is to describe in detail how Study Two was conducted. The chapter was structured to reflect the timeline of the study going from the design to the discussion of results. Points of participatory data analysis are reported in the order they happened.

Introduction

The findings of the systematic review pointed to the need of a revised definition of loneliness that should include subjective autistic experiences, wide participation of the autistic community, and exploration of strategies that are personally meaningful to autistic young people. The second study was designed to address these needs and sought to explore the experiences of loneliness for autistic young people qualitatively and with the use of creative and flexible methods of research. Also guided by the findings of the first study, this investigation aimed to expand the commonly used conceptualisation of loneliness, which is limited to its social and emotional domains. The systematic review showed that traditional ways of investigating loneliness as a bidimensional construct have been widely adopted and used as a theoretical framework for the development of many measures of loneliness. However, they have left large gaps in understanding how loneliness is experienced by different groups of people (Fried et al., 2020; Schmidt, 2023).

Autistic people reportedly have high rates of loneliness (Deckers et al., 2017; Ee et al., 2019), and whilst many scholars and advocates have explored the topic, the unique ways in which autistic people experience loneliness and connection remain an evolving field of

study. Early research by Bauminger and Kasari (2000) reported that having a best friend did not seem to lessen feelings of loneliness for autistic children, raising questions as to what contributes to meaningful experiences of connection and belonging. For example, Social Motivation Theory proposes that autism may be associated with differences in social motivation, including social orienting, social reward and social maintaining (Chevallier et al., 2012). From this perspective, social interactions may not always hold the same motivational value for autistic and non-autistic people. This adds further complexity to understanding loneliness for autistic young people, as reduced social interaction or a preference for spending time alone cannot necessarily be interpreted as evidence of loneliness. At the same time, differences in social motivation should not be understood as an absence of desire for social relationships, as autistic people vary considerably in their preferences for social connection and in their experiences of loneliness. In this thesis, openness to exploring personal accounts of connection and belonging meant that social motivation was not assumed to be predetermined or uniform.

Subsequent research has reinforced this complexity. Although autistic individuals define friendships similarly to their non-autistic peers, they also mention unique challenges to developing and maintaining social relationships, including differences in social norms and communication style (Black et al., 2024). Anxiety, fear of judgement and a poor self-image might also compromise the development of relationships in which autistic people feel accepted and authentic (Black et al., 2024).

Many autistic people have expressed a desire to have and maintain friendships (Gallup et al., 2016; Murphy et al., 2017; Myles et al., 2019), however, some autistic young people describe pursuing friendships in order to be considered ‘normal’ (Berns, 2016) or prefer spending time alone (Goodall & MacKenzie, 2019). These findings suggest that loneliness for autistic young people cannot be reduced to the presence or absence of

meaningful social relationships. Rather, experiences of loneliness might be shaped by whether autistic people feel understood, accepted and authentic. In line with this argument, Grace et al. (2025) found that loneliness for autistic adults is not solely determined by unmet social needs, but also by the lack of shared experiences with the wider population and a lack of understanding of autism in society. These findings highlight that feelings of loneliness can go beyond the traditional conceptualisation of social and emotional loneliness.

The findings of the systematic review that preceded this study (Lisboa White et al., 2024) support the assumption of multiple realities of loneliness by raising three points specifically relevant to the study of loneliness for autistic young people. First, loneliness has rarely been defined by autistic people and has not previously been investigated as the main topic of qualitative research. This indicates a non-verified assumption that loneliness is experienced similarly by autistic and non-autistic people. Second, feeling connected, or 'not lonely' has been limited to measures of social relationships, such as satisfaction with friendships. This reductionist view contradicts findings that suggest autistic young people may experience connection differently. Third, scales that do not include autistic perspectives have been consistently used to investigate loneliness for autistic young people, possibly overlooking the different ways in which loneliness can be experienced.

Overlooking lived accounts of autistic people has been highlighted as an issue in autism research (Caruana et al., 2021; Cassidy et al., 2018a; Cassidy et al., 2018b; Fletcher-Watson et al., 2019; Grace et al., 2022; Milton & Bracher, 2013). Concerns have been raised about measures that have not been designed or validated with autistic people (Nicolaidis et al., 2019). Although possibly unintended, the omission of autistic perspectives on how loneliness is experienced reinforces a historical trend of defining autism based on social deficits rather than on differences or social contexts (Milton et al., 2023). Despite good intentions, this risks offering "neurotypical help" (Elmose, 2019, p. 20). Including autistic

voice as part of research can help to enrich findings by improving epistemological integrity and by allowing access to first-hand accounts on relevant questions relating to wellbeing (Milton & Bracher, 2013).

This study considered both the multifaceted lived experiences of loneliness and its diverse theoretical perspectives, recognising the multiple realities of loneliness (Gedvilaitė-Kordušienė, 2017). Lesser-explored dimensions of the construct that come from feelings that are unrelated to social interactions were explored. Existential loneliness, for example, can be defined as a feeling of being fundamentally separated from others or the world (Baek et al., 2023) and experiential loneliness is when someone feels misunderstood by others (Stein & Solomon, 2017). Similarly to social and emotional loneliness, existential and experiential loneliness also evoke negative emotions including sadness, alienation (Larsson et al., 2017; Sjöberg et al., 2018), and abandonment (Ozanne et al., 2013). However, a person can experience existential and experiential loneliness even if they feel their social relationships are satisfying both in number and quality (Bolmsjö et al., 2019; Larsson et al., 2019). Investigation that adopted these other domains of loneliness enabled researchers to understand how certain vulnerable groups, such as people with mental ill health, people receiving palliative care, people with cancer and chronic illness and elderly people in care, experience loneliness (Bolmsjö et al., 2019).

In addition to these less explored facets of loneliness, philosophical perspectives offer a contrasting view to how psychology has investigated the construct. Under this lens, although painful, loneliness can be seen as a transformative and necessary experience that enables spaces for creativity, reflexivity, emotional growth and dialogues with the self (Mosé, 2018). This is not to be confused with solitude, which has been defined as being alone in the absence of distress or suffering (Tillich, 1963) and critiqued by philosophical perspectives as a term that can impoverish the comprehension of human experience (Mosé, 2018). Instead,

philosophical understandings of loneliness propose that suffering should not be separated from the experience of loneliness, as it is through engaging with this discomfort that possibilities of personal growth and connection with the self will emerge (Kierkegaard, 1992; Moustakas, 1961; Nietzsche, 2009).

Informed by these broader theoretical approaches to loneliness and engaging with lived experience through creative and flexible methods, this study proposed a revision of the conceptual definition of loneliness to include personal authorship from autistic people. It explored how a small group of autistic young people described their experiences of loneliness. The research questions that guided this participatory exploration were a) how do autistic young people experience loneliness? and b) what personal strategies promote feelings of connection and wellbeing?

Community Involvement

Participatory research is common in many different fields of enquiry such as nursing (Hallam-Bowles et al., 2022), public health (Demkowicz et al., 2025) and indigenous culture (Del Pino et al., 2025). Historically, autism research has been mostly led by non-autistic researchers with little input from autistic people (den Houting, 2021; Donavan & Zucker, 2016). With the growth of the neurodiversity movement through representation in popular culture (Jones et al., 2023), the rise of self-advocacy (Leadbitter et al., 2021), as well as influential papers published by autistic scholars (Kapp et al., 2019; Milton, 2012; Sinclair, 1999), the use of participatory frameworks has become a force in amplifying autistic voice and a marker of excellence within neurodiversity research (Fletcher-Watson et al., 2021). In addition, research that invites lived experience of non-scientists into the many steps of the investigation process has the potential of producing more relevant outcomes, which will be impactful and more aligned with people's values and priorities (Hutchen & Oliver, 2021; Pellicano & den Houting, 2022).

This study invited autistic views at several points of the research process. Autistic people contributed to the design of the study, to data analysis and discussion of results. Instead of trying to define the evolving concept of participatory research, the focus here will be to articulate how principles and values have been translated into practice throughout the study (Masterson et al., 2022). This approach is a promising way forward that considers the diverse ways in which research can be carried out and how wider participation can be achieved (Smith et al., 2022). The values underpinning autistic participation in this study were of flexibility, inclusion, and balance of power (Freire, 1967).

Flexibility was translated into practice by giving people choice in how they wanted to take part in discussions. For every proposed activity there were different modes of participation (Table 8).

Table 8

Ways in Which Autistic Young People Engaged With the Qualitative Study

Activity	Modes of Participation
How to take part	Individually In groups In person Remotely
How to express opinions and views	Typing Talking Writing Drawing Ranking visual prompts Interacting through online platforms
How to access materials, questions or discussions	Reading on screen Reading on a hard copy By listening

In addition, a proactive approach to participants' requests was adopted. For example, one person who was consulted about the design for the study asked to take part in the panel individually and to be supported by a familiar person. Participatory research is characterised by collaboration, complexity and a degree of messiness (Cook, 2021). Giving voice to the

typically unheard can only be possible by following unorthodox pathways, by reinventing, reimagining and accepting uncertainty. Allowing flexibility in how views and contributions were gathered and being open-minded to suggested novel modes of participation, were ways to foster an inclusive environment.

Inclusion was reflected in practice by accounting for possible differences in communication, social skills, cognitive overloading, mobility, accessibility and sensory sensitivities. To welcome differences in communication and social skills, for example, besides the many different modes of participation cited previously, responses were not expected to be given within a typical time frame. People were made to feel welcome if they needed more time to formulate and express their views, and for some activities, people had the choice to have visual prompts. Having the choice to write or draw their answers, rather than speak, gave people the opportunity to work in their own pace, allowing space and time for reflection, revision, elaboration and expression of ideas. Cognitive overload was considered, and people were told they were welcome to have breaks whenever they felt the need to.

People who took part in the study were welcome to use their own personal strategies to promote comfort and wellbeing. Examples include participants who wore sunglasses, ear defenders, or hoodies over their heads. One asked to have the lights turned off, and some had a fidget toy throughout the session. Mobility and accessibility differences were welcome by offering participants options for taking part in a familiar place (such as their education provider, where accommodations were expected to be in place) or remotely (via Teams). Unfortunately, not all accessibility differences could be accounted for due to administrative difficulties. People taking part in the different phases of consultation did not have their travel costs covered nor were they offered different options for payment that would allow them to consider implications on benefit claims (Woodward et al., 2022).

One of the main focuses of participatory research is "the transformation of power structures and relationships" (Maguire, 1987, p.37). Power imbalances were addressed with the adoption of everyday language, a friendly tone and casual clothing. When interviewing people, the researcher sat next to them (as opposed to across from them) making sure that there were no tables or objects in between. Building rapport and trust before any formal discussions were done by familiarisation meetings, informal chats about participation, email exchanges about accommodations of specific needs and friendly exchanges around people's interests, schoolwork or how their day had been. Light refreshments were offered in every encounter with the intention of making sessions more informal and comfortable.

More details about how autistic views were invited at the different points of the study will be given in the sections below to reflect the timeline in which they took place and to highlight young people's unique contributions.

Methods

Aligned with open research practices that aim to support transparency and rigour in qualitative research (Haven & Van Grootel, 2019), this study was pre-registered on the Open Science Framework (OSF) platform. The protocol can be accessed via the link, https://osf.io/3vu64/overview or a copy of the form can be seen in Appendix B. Ethical approval was received from the School of Education, Language and Psychology Research Ethics Committee at York St John University (ETH2324-0127). Amendments to incorporate participatory data analysis were approved (ETH2425-0015).

Funding

All sessions of participatory data analysis were funded with a grant from the Waterloo Foundation (Ref no. 3876-7705) (Appendix A).

Design in Consultation with Autistic People

Popular creative methods used to explore personal experiences include diary entries (Hilario & Augusto, 2023), online personal blogs (Lisboa White & Staniford, 2023; Petty & Noddings-Walker, 2025), photovoice (Lam et al., 2020; O'Brien, 2017), free listing (Petty et al., 2023), object elicitation (Willig, 2017), graffiti (Li & Liu, 2023) carousel of methods and immersive theatre (Batsleer & Duggan, 2021). Creative and flexible methods promote better and more meaningful participation (Lewis et al., 2024) and contribute for more fluidity and openness in the research process (McArdle, 2022). This approach is aligned with the ontological underpinning of this thesis, which views knowledge as multiple, and that understanding of human experiences must be partial and contextualised, rather than being focused on finding one truth (Braun & Clarke, 2022b; McArdle, 2022).

The adoption of creative and flexible methods in autism research allows for a much-needed autistic representation and fosters access to the diverse strengths and interests of autistic individuals (Lewis et al., 2024). Thinking of different ways in which people would like to engage with research is a way to reflect and respect the diversity within the autistic community (den Houting, 2021). The process of designing new methods of data collection and planning more inclusive ways in which research can be conducted is better informed when power is shared (Nicholaidis et al., 2019), and the members of the community are involved in decision-making stages. Based on this argument, autistic people were invited to evaluate a list of methods of data collection and decide which would be the best to engage autistic young people in research.

Relevant literature was searched to select a list of methods. Consideration was given to reported levels of engagement, flexibility and openness of each method, their suitability for schools / colleges and their adaptability to be used online. Doctoral theses were an important source of inspiration, particularly Berns (2016) and Rossetti (2007), whose work provided insights into conducting research in inclusive and flexible ways. Berns (2016) looked at how

autistic male adolescents perceive and experience friendship, mentioned the need to address differences in communication and social skills, and adopted drawing as a way of collecting perspectives from autistic participants. Rossetti (2007) who investigated the experiences of friendship for people with developmental disabilities, described how different modes of communication including typing and eye gazing were included in their investigation. Ridout (2017) added to the repertoire of flexible methodologies by introducing narrative diaries and collage used to explore individuals' experiences of autism. Ridout described how flexibly these methods were used, and how they introduced four key points during the generation of data where participants could continue to engage or disengage with the process. In the present study, 'checking points' with participants were adopted during consultation, data collection and participatory data analysis informed by Ridout's report. Lewis et al. (2024) presented useful illustrations of how flexible methods could work in practice. They offered rich descriptions illustrated with pictures of how they used visual and embodied methods of data collection. Giving participants choice in how they engaged with research was also reported to empower participants to voice their experiences without being dependent on verbal competencies. Ideas for creative and flexible methods of data collection generated from searching these materials were taken to supervision meetings.

Discussions with supervisors considered ways in which to adapt some of the methods found in literature, how to improve them or reinvent them using other tools. New ideas and possibilities based on the principle of enabling different forms of participation were brainstormed. In the end, seven methods of data collection were chosen to be reviewed and evaluated by consultation panels of autistic people. The methods chosen were semi-structured interviews, focus groups, public wall of thoughts, virtual wall of thoughts, written diaries, photovoice, and art-based interviews.

Consultation groups of autistic people (*N*=9, 6 females) evaluated methods of data collection through PPI groups. Recruitment was aimed at young people, 18 years old or older. Sessions for these groups considered the same values of participatory research described above – flexibility, inclusion, and balance of power – and were planned accordingly. Panellists were students from a specialist college (*n* = 4) and students in their first year of undergraduate Psychology degree (*n*=5). Six participants had formal diagnoses of autism, three identified as autistic with one pursuing a formal diagnosis. Panellists were offered £10 vouchers for their participation, funded by the research fund for postgraduate studies at York St. John University. There were four sessions in total each lasting approximately 60 minutes.

Sessions were structured around presenting the seven methods of data collection, followed by discussions about each method. Participants were invited to speak, but participation was also supported by other means. For the sessions hosted at University, Mentimeter was used as a tool to introduce each method and support communication. Posts on Mentimeter were anonymous. Sessions at the specialist colleges had the activities adapted to paper, as they did not have access to Wi-Fi within the premises. Participants talked about each method and made notes on the printed presentations.

Methods of data collection were ranked by the panellists from most-to-least suitable accompanied by reasons why they would engage or not with each method. For example, comments on the use of a public wall of thoughts highlighted concerns that young people might feel exposed, as their handwriting could be recognisable. Participants added that thoughts previously recorded on the wall and visible to everyone could influence young people's contributions, possibly compromising authenticity. To counter these limitations, panellists suggested offering young people 'a box of thoughts' instead, where their writing would be concealed from other participants. Diaries were not popular amongst the consultation groups: "The last thing I would've wanted to do in high school is write a diary –

potential to be read through by others and just seen as not a very cool thing to be doing" (anonymous post). Other negative comments were about the difficulty of engaging with this type of activity and remembering to write on it every day.

Using creative methods such as collage and other forms of art was well received by panellists: "Can be a fun and creative way to express yourself, I would engage with this" (anonymous post). Some of the suggestions for using this method of data collection included offering individual sessions, where participants could focus on expressing themselves authentically rather than comparing themselves to others. It was suggested that individual sessions could possibly minimise problems with sensory overload and anxiety generated in group settings.

Many panellists expressed a preference for semi-structured interviews, with some suggesting this would be the most appropriate method for exploring experiences of loneliness with autistic young people. However, they suggested that the interview should be designed with open questions – more like a conversation – as this would promote engagement: "I feel personally that conveying through conversation is sometimes just the best way to get a thought or a feeling across. And having set questions can sometimes present a way to convey the process" (anonymous post).

Although the intention of this consultation was to elect a single method of data collection, there was strong agreement amongst panellist that offering autistic young people choice in how they engaged with research would be the best approach. One PPI group was particularly vocal about the individual differences within the autistic community. They noted that asking autistic people to work in a pre-determined way or fit into categories could lead to low or no engagement. The recommendation was to offer a choice of adaptable methods, making people feel comfortable.

Offering choice and flexibility in how participants can engage in research reflects how principles of the neurodiversity paradigm and social model of disability can be put into practice. Considering diversity and social contexts helps to broaden medicalised views based on individual deficits (Pellicano & den Houting, 2022). The emphasis given by panellists to the adaptability of methods indicates the community's interest in making research participation accessible. Offering choice in how participants can contribute data might help autistic young people to feel part of the research process. This suggestion was incorporated to the study design, and participants were offered three of the highest-ranked methods identified by the consultation panels: semi-structured interviews, art-based interviews, and anonymous posts on a virtual wall of thoughts. The three methods are explained in more detail below.

Materials and Procedures

Semi Structured Interviews. Semi-structured interviews are a suitable method for qualitative data collection when the researcher aims to co-create meaning with those being interviewed (DiCicco-Bloom & Crabtree, 2006). A protocol (Appendix C) was planned informed by literature (McGrath et al., 2018; Smith, 1995) and guided the interviews.

There were three areas of interest to be explored with participants: the familiarity with feelings of loneliness, personal conceptualisations of loneliness and non-loneliness. The first questions and prompts were designed to find out if participants had felt lonely before, and if so, how frequently they felt lonely and under what circumstances. The questions also aimed at understanding if loneliness was considered a positive or negative feeling and what kinds of emotions were associated with it. There were questions about the meaning of loneliness, prompting participants to describe it and give examples of when they felt lonely: "Can you give me an example of when you felt lonely?" and "Can you describe what you felt?" The questions also included exploration of what feeling 'not lonely' might feel like with questions such as "What is the opposite of loneliness?" and "Can you give me an example of when you

felt like that?". The main questions and prompts were discussed with the supervisory team. Consideration was given to the language being used and its alignment with the aims of the interview, and to the clarity of the questions (McGrath et al., 2018).

At the start, the protocol included a photo elicitation at the end of the interview, where participants were invited to bring pictures or objects that helped them reflect about their experiences of loneliness. None of the participants brought materials that could be used therefore, elicitation was not used during the interviews. All participants who chose to take part in semi-structured interviews asked for them to be done individually and in person. Interviews averaged 28 minutes, were audio recorded and transcribed.

Art-Based Interviews. The use of visual arts-based research has been successfully used with marginalised groups, encouraging creativity and reflexivity (Holm et al., 2018). It is a tool that can produce multiple meanings since it relies on the interpretations of the viewers and their context. This dynamic decentralises knowledge production; the academic is no longer the 'expert', but a viewer that encourages dialogue to evoke meanings rather than denoting them (Leavy, 2020).

For art-based interviews, participants were asked to create a piece of art related to their experiences of loneliness. They were encouraged to use any type of visual art they felt comfortable with including drawing, painting, collage or digital art. A box containing art supplies was offered (felt-tip pens, drawing pencils, pens, colouring pencils, soft pastel sticks, colourful paper, textured paper, patterned paper, scissors, glue, card, stencils, ruler and tape). Some participants chose to use their own materials (for example, watercolour). Art pieces were used as a conversation starter between the participant and the researcher, who initially invited participants to talk about their piece and further prompted them to elaborate on their experiences of loneliness.

All participants who chose this method of data collection asked for the activity to be carried out individually and in person. Participants took 40-50 minutes to complete their artwork, and interviews averaged approximately 21 minutes of discussion. All pieces of work were photographed, with the original piece taken away by the participant at the end of the session. All interviews were audio recorded and later transcribed.

Anonymous Virtual Wall of Thoughts. Participants who chose to contribute to the anonymous virtual wall of thoughts were provided with a QR code that gave them access to a Padlet (a web-based digital bulletin board platform that allows users to create, share and collaborate on virtual walls in real-time). There, they found prompts which included "I feel lonely when / if / every time I...", "I feel connected when / if / every time I...", "Loneliness is...", "Connection is...", "Loneliness feels...", and "Connection feels...". Participants were invited to post anonymous comments and/or pictures. This method was brainstormed during supervision meetings when looking for alternatives to accommodate communication differences. Offering people the opportunity to communicate according to their preferences, can facilitate the exploration of sensitive topics whilst democratising participation (Ridout, 2017). All participants who chose to contribute to the anonymous virtual wall of thoughts asked for the activity to be carried out individually and in person. Participants were given time to add posts during a data collection session and could continue to contribute to the wall after the session if they chose to.

Participants were offered light refreshments during all sessions and the option to take part in the draw of two £25 vouchers. These sessions were funded by the research fund for postgraduate studies at York St. John University.

Participants

Initially, the age range for participants included autistic young people from 12 to 18 years old, based on conceptualisations of adolescence from the literature (Dahl, 2004; Jaworska & MacQueen, 2015). However, after presenting the project to a group of prospective collaborators, it was suggested by some autistic young people that the age range should be expanded. Some young people were older than 18 and thought they could still contribute to the project, being familiar with feelings of loneliness through their adolescence. The age range was modified to reflect the participatory ethos of the study.

A total of 26 young people (*M*=17.11, *SD*=2.77) with a formal diagnosis of autism were recruited from specialist colleges (*n*=17), selective schools (*n*=5), independent schools (*n*=2), and mainstream secondary schools (*n*=1) in the UK. One student was out of education. Participants identified as male (*n*=13), female (*n*=9), non-binary (*n*= 3), and transgender (*n*=1). Participants identified as white British (*n*=21), any other white identity (*n*=2), Asian British (*n*=1), British Pakistani (*n*=1), and any other ethnic group (*n*=1). Specialist colleges were post-16 years education providers focusing on creative study programmes for neurodivergent students. All participants were given an information sheet and asked to sign a consent form if they understood this and were willing to take part. Parental consent was given for people younger than 18 years old. All participants were asked for their assent at the start of the data collection sessions. Formal diagnoses of autism were confirmed by parents or education providers. Participants names were anonymised, except where they explicitly asked to be identified. This was adopted to respect preferences regarding attribution.

Data Collection

Qualitative researchers are interested in examining solicited and unsolicited narratives of lived experience (Burles & Bally, 2018) and can adopt an array of methods for giving voice to participants. The focus of this study was to understand how autistic young people experience loneliness and to gather personal strategies that promote connection and soothe feelings of loneliness. The aim was to be inclusive by introducing creative and flexible methods of data collection that could facilitate and encourage autistic young people's engagement.

Participants were presented with three methods of data collection and selected the methods they wanted to engage with (some chose more than one) and how they wanted to engage (in person, remotely, individually, or in groups) (Table 9). A qualitative dataset was composed of 19 semi-structured interviews, five art-based interviews, and 14 written anonymous posts from seven participants. Data collection session took place at participants' schools, colleges and at York St. John University.

To prepare the dataset for analysis, all interview recordings were transcribed using an online AI-powered transcription service that converts audio files into text. Before opting for this service, data security and privacy features were checked. All files are encrypted; accounts are personal and password protected and only the account holder has access to uploaded files and transcriptions. Users have full control of data, being able to export or permanently delete files at any time (Turboscribe, 2025). All automated transcriptions were enhanced by manually editing the transcripts against the audio recordings (for an example, see Appendix D). Editing consisted of correcting errors, capturing non-lexical sounds and pauses that were relevant for representing speech (Clarke, 2025).

Table 9

Methods of Data Collection Chosen by Participants

Pseudonym	Type of School	Age	Gender*	Ethnicity	Interview	Art-based interview	Virtual wall of thoughts
Adam	Specialist College	18	M	White British	✓		
Alex	Selective School	16	M	White British	✓	✓	✓
Ashleigh	Specialist College	19	F	White British	✓		
Bethany	Selective School	14	F	White British		✓	
Ben	Specialist College	17	M	White British	✓		
Charlie	Specialist College	18	F	White British	✓		
Edward	Specialist College	18	M	White British			✓
Ellie	Independent School	12	F	Any other white background			✓
Esther	Specialist College	18	NB	White British	✓		
Evelyn	Specialist College	15	F	White British	✓		
Georgia	Independent School	12	F	Any other white background		✓	
Indiana	Specialist College	17	NB	White British	✓		
Jacob	Selective School	17	M	White British	✓		
James	Selective School	17	M	White British	✓		
John	Specialist College	20	M	White British	✓		
Joseph	Specialist College	20	M	White British	✓		✓
Kass	Out of education	13	T	White British		✓	

Laura	Selective School	17	F	White British	✓		✓
Manisha	Specialist College	17	F	Asian British	✓		
Max	Mainstream	12	M	White British	✓		
Parker	Specialist College	17	M	White British	✓		
Qamri	Specialist College	23	F	British Pakistani	✓		
Richard	Specialist College	18	M	White British		✓	✓
Sadie	Specialist College	19	NB	White British			✓
Sean	Specialist College	23	M	White British	✓		
Tony	Specialist College	18	M	Any other ethnic group	✓		

*M=Male, F=Female, NB=Non-Binary, T=Transgender

Analysis

Data were analysed using Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2022a; Trainor & Bundon, 2021). This method was chosen after considering aspects of the project, such as the research questions guiding the investigation, the diversity, size, and complexity of the dataset, as well as the use of participatory data analysis and the broader ontological and epistemological underpinnings. RTA is described as a non-positivist framework, guided by qualitative research values such as the understanding of knowledge as being contextual and partial (Braun & Clarke, 2022a). Previously in Chapter Two, when considering ontological perspectives, positivist underpinnings were discussed as being inadequate for investigations that aim to include lived experience in autism research. There is significant critique of studies that have used autistic people as passive objects of their investigation, producing results that dismiss autistic subjective experiences (Botha, 2021; Milton, 2014a). One of the aims of this study was to investigate autistic perspectives of

loneliness, under the assumption that there are multiple realities of the construct (Gedvilaitė-Kordušienė, 2017), making RTA a good fit from a philosophical and theoretical point of view.

RTA has been successfully used to analyse diverse types of data such as in-depth interviews (Byrne, 2022), social media posts (Turner et al., 2023), and blogs (Petty & Noddings-Walker, 2025). Similarly, visual methods combined with interviews (Culshaw, 2019) or with narrative diaries (Ridout, 2017) have been used as creative and flexible ways to collect qualitative data. The data in this study were anonymous written posts, in-depth semi-structured interviews and art-based interviews requiring a flexible method of analysis (Byrne, 2022). RTA was suitable to deal with the complexity and diversity found in the dataset and the different voices producing knowledge.

The participatory approaches of the project were also aligned with the 'Big Q' qualitative values that characterise RTA (Braun & Clarke, 2022b), emphasising a focus on deepening and enhancing the researcher's interpretation of the data. In this context, participants' engagement with the coding and preliminary results served as a tool to generate additional insights and add nuance to the understanding of the dataset. More details about how participatory data analysis was incorporated to the study are offered in specific sessions below.

In summary, the project's philosophy, theory and methods were conceptually coherent (Willig, 2013) with the choice to use RTA. The analysis was based on "immersion, creativity, thoughtfulness and insight" (Braun & Clarke, 2022b, p. 268) rather than positivist notions of accuracy or reliability. The use of RTA offered the opportunity to adopt a critical relativist perspective (Porpora, 2015) contributing to the development of alternative conceptualisations of loneliness for autistic young people, as opposed to a single 'truth' (Burr, 2015). This was

achieved by valuing all modes of participation equally and by recognising the insights from the different forms of expression (spoken, written or visual). Conflicting views were also welcome into the analysis through the use of participatory inclusive frameworks (Chown et al., 2017; den Houting, 2021). All these choices and methods adopted throughout the study aligned with the ontological shift in autism research towards identifying and promoting affirmative practices that autistic young people can benefit from (Milton, 2012; Sonuga-Barke, 2023).

Familiarisation

Familiarisation is the process by which the researcher gets to know the data more intimately (Byrne, 2022) to the point of being able to describe the overall content (Braun & Clarke, 2022b). A significant contextual understanding of the data was achieved by carrying out data collection, by editing transcripts, by capturing images of the visual data and by interacting with all the participants (Byrne, 2022). After conducting interviews, automated transcriptions were done as soon as possible, as well as the editing of transcripts against the audio recordings. Formatting the transcripts, correcting errors, adding non-verbal utterances, pauses and filler words, revived the memory of each interview. Pieces of artwork produced by participants were revisited during the familiarisation phase together with their respective interviews. Each piece of artwork was photographed several times. Formatting these images and organising them in digital folders was useful to see them from different angles and in different light. Familiarisation with visual data included engaging with the art piece and making conscious observations about space, colour and texture use. Notes were made on the presence or absence of human characters, elements from nature, shapes, or abstract components. The intensity of lines and shades was observed as well as the materials used and the degree of detail. These perceptions were complemented by verbal characterisations given by participants. Anonymous written posts were also revisited by exporting them to a PDF file

which made them clear and easy to read and re-read. During this intense exposure to the data, central topics relevant to the research questions and addressed by each participant were mentally highlighted.

Once the transcripts were fully edited, the visual data had been formatted and the posts had been exported from Padlet, a second phase of familiarisation took place. This time, all elements of the dataset were revisited and notes were made, capturing general ideas about how loneliness was felt and described. These notes recorded both analytical and personal observations of the data, such as possible trends and patterns but also, first impressions, feelings and thoughts (Terry & Hayfield, 2025). Notes were kept on a Word document in the form of a reflexive journal (Table 10) (Braun & Clark, 2022b).

Table 10

Examples of Entries in the Reflexive Journal During Familiarisation Phase

Date	Entry
01/07/2024	"After transcribing Richard's and Joseph's interviews: the impression is that they need connection with people, but for different reasons. Their need for people does not seem to resonate with the typical dimensions of emotional and social loneliness, but more like support. For Richard, connections with people seem to support his rich inner life, which is enough for him to feel not lonely. For Joseph, it is important to feel acknowledged. Connections with people are important for him to feel taken care of – it's linked to mental health."
20/08/2024	"Parallels between Indiana's and James' interviews. It seems that loneliness is not felt as badly when young. Social contact is not interpreted as important. This sphere of life seems to be ranked as a skill like any other, which you can be good or bad at it, with no consequence to your wellbeing."

The reflexive journal included a combination of entries on evolving perceptions, evaluation of day-to-day procedures, personal introspections and developing insights

(Lincoln & Guba, 1982). These were useful to inspire areas for further study that would later influence deductive coding. For example, later notes about Indiana's transcript described how they talked many times about being content on their own, but also mentioned a worry for their future, for being alone and for their mental wellbeing. They said pressure to have relationships could be both extrinsic and intrinsic. The familiarisation notes included a question: "Could this pressure be socially constructed?" and added a reminder to "find out more about parallel play and socially constructed ideas of happiness".

Keeping a reflexive journal during the analytical process was a tool to engage with data. It documented emotions, biases and how interpretations shifted, contributing to the process of sense-making (Olmos-Vega et al., 2023). Some of these first impressions were taken forward as the analysis progressed.

Coding

Generating codes in RTA is done to capture specific meanings and translate them into a label that offers some contextual interpretation of the data being analysed (Braun & Clarke, 2022b; Byrne, 2022). For this study, codes were assigned in an iterative process and were revised after every round by the supervisory team (for an example, see Table 11). Interview transcripts were saved as individual files on Microsoft Word and codes were assigned to highlighted parts of the text using the comments tool.

The research questions guided the coding process a) how do autistic young people experience loneliness?; and b) what personal strategies promote feelings of connection and wellbeing? As this study was primarily interested in the experiences and perspectives offered by participants, an inductive approach was adopted for the first round of coding (Braun & Clarke, 2022b).

During the second round of coding, a deductive approach connected the data with existing theories of loneliness and autism research (Byrne, 2022). This meant, for example, adding codes that reflected existing conceptualisations of loneliness such as emotional and social loneliness (Weiss, 1973), existential loneliness (Bolmsjö et al., 2019), and experiential loneliness (Schmidt, 2023). Semantic and latent characteristics of the data were of interest during coding and both descriptive and conceptual meanings were considered.

Table 11

Example of How Coding Was Assigned to Highlighted Text

	Interview excerpt	Code
LLW:	Okay, and do you feel, have you ever felt lonely in your life?	
Tony:	Yeah, I have, yeah, I have, a lot of, yeah, a lot of my life, yeah.	Self-reported loneliness – familiar with the feeling
LLW:	Okay, do you feel lonely now, at the moment, here at [name of college]?	
Tony:	Um, there are times I do feel like that, I won't lie.	Loneliness amongst familiar people.
LLW:	Okay, is it a positive or a negative feeling?	
Tony:	It (.) It, it, it's weird, but as you, you, you, sorry I'm stuttering, you can say negative, just negative, you know, I guess. It's weird, sometimes it's good, sometimes it's negative.	Loneliness is ambiguous (positive or negative)
LLW:	What kind of emotions do you associate with it, what, how do you feel inside when it's negative? Or what do you feel like doing when it's negative?	
Tony:	When it's negative (.) I've, like, this is going to sound really selfish, but I've even, like, cos I get the feeling of loneliness, even if I'm with the people who are closest to me, or if I'm in a room full of people, I still	Feelings of loneliness around close people

	feel lonely. And, um, I have this thing, sorry, I look at stuff when I'm talking, that's not good.	Feelings of loneliness in a room full of people

During an inductive approach to coding, semantic codes were more prevalent and captured participants' descriptions of emotions and circumstances associated to feeling lonely or not lonely. These codes captured characterisations of loneliness and were close to the participants' words. An example is when Jacob (17) described the people he felt connected with, "my people is the people who have similar interests, similar values, similar senses of humour, and we kind of can all connect about the same thing". This extract received the code "Connection happens through common ground (similar interests)", which captures in a few words the explanation given by the participant.

A deductive approach was adopted for the second round of coding, which offered an opportunity to reflect on latent meanings of the dataset supported by theories of loneliness and wider theories relevant to autism research. These codes captured for example, how socially constructed ideas of connection can influence how autistic young people feel about their own ability to connect with others. An excerpt that illustrates this is when Adam (18) described his choice to be lonely,

> *I chose to be lonely because I couldn't handle other people. I found people too complicated, and I didn't want to deal with it. And I didn't want to deal with my own emotions, and I didn't know how to do anything cos I had no guidance on how to t-, handle any situation*.

The codes assigned to this extract were "loneliness comes from lack of guidance from others", "loneliness comes from lack of personal skills", "Double empathy problem". These codes reflect semantic and latent aspects of the text. The first two codes described

circumstances where Adam felt lonely, staying close to his own words. The third code interprets his perceived 'lack of ability' to connect with other people as a symptom of the dispositional gap described by the double empathy problem (Milton, 2012). This deductive approach to coding served to add a critical and theoretical lens to the analysis.

Phase 1 of Participatory Data Analysis: Evaluation of Codes

After two rounds of coding, all participants who had contributed data to the study were invited to take part in data analysis through two different tasks: evaluating codes and creating candidate themes. Eleven participants chose to engage with data analysis. To maintain confidentiality participants were presented with coded data extracts from their own interviews. Sessions were carried out individually, in person and were audio recorded when participants chose to do the evaluation orally. Participants received a £20 voucher for every session of participatory data analysis they took part in (during phases 1 and 2), and light refreshments were available throughout the sessions. The grant offered by the Waterloo Foundation (Appendix A), funded the costs with these sessions.

All participants were new to data analysis. To ensure meaningful engagement and following successful accounts of community peer research (Barke, 2025), some training was planned for the beginning of each task. For the first task, this consisted of a brief explanation of what a code is and what it is used for in qualitative research, followed by a few examples of how coding was completed for the participant's transcript. Next, participants were given suggestions on how to engage in the evaluation of codes by agreeing, disagreeing, adding or deleting codes. These suggestions were printed and accessible at all times (Figure 5).

Participants were also encouraged to come up with their own ways of interacting with the dataset by for example rephrasing codes, adding to an existing code without completely replacing it, drawing on the margins or highlighting words. Some participants chose to

evaluate codes silently whilst making notes on the sheets; others asked for the excerpts and codes to be read out loud whilst their views were noted by the interviewer (for examples, see Figures 6 and 7. Please note that the highlight markings were done by LLW to facilitate analysis).

Figure 5

Suggestions Given to Participants on How to Engage with Evaluation of Codes

Task 1: Evaluate codes

You can use this key or come up with other ways of interacting with your dataset:

I agree with this code	
I disagree with this code	
Write a new code (You can add new codes to the dataset)	
Delete a code	~~code~~

Figure 6

Example of Evaluation Sheet Annotated by Participant

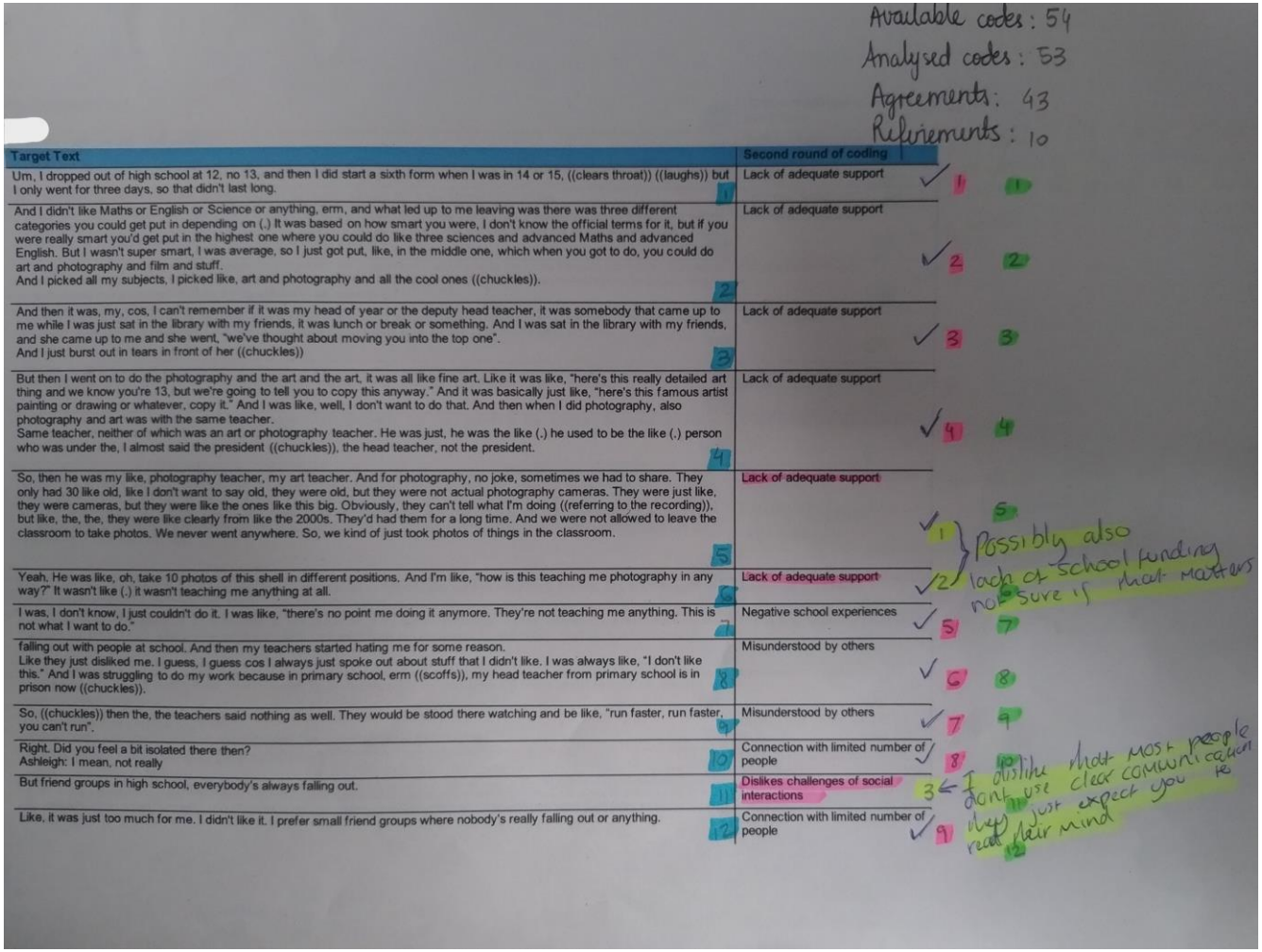
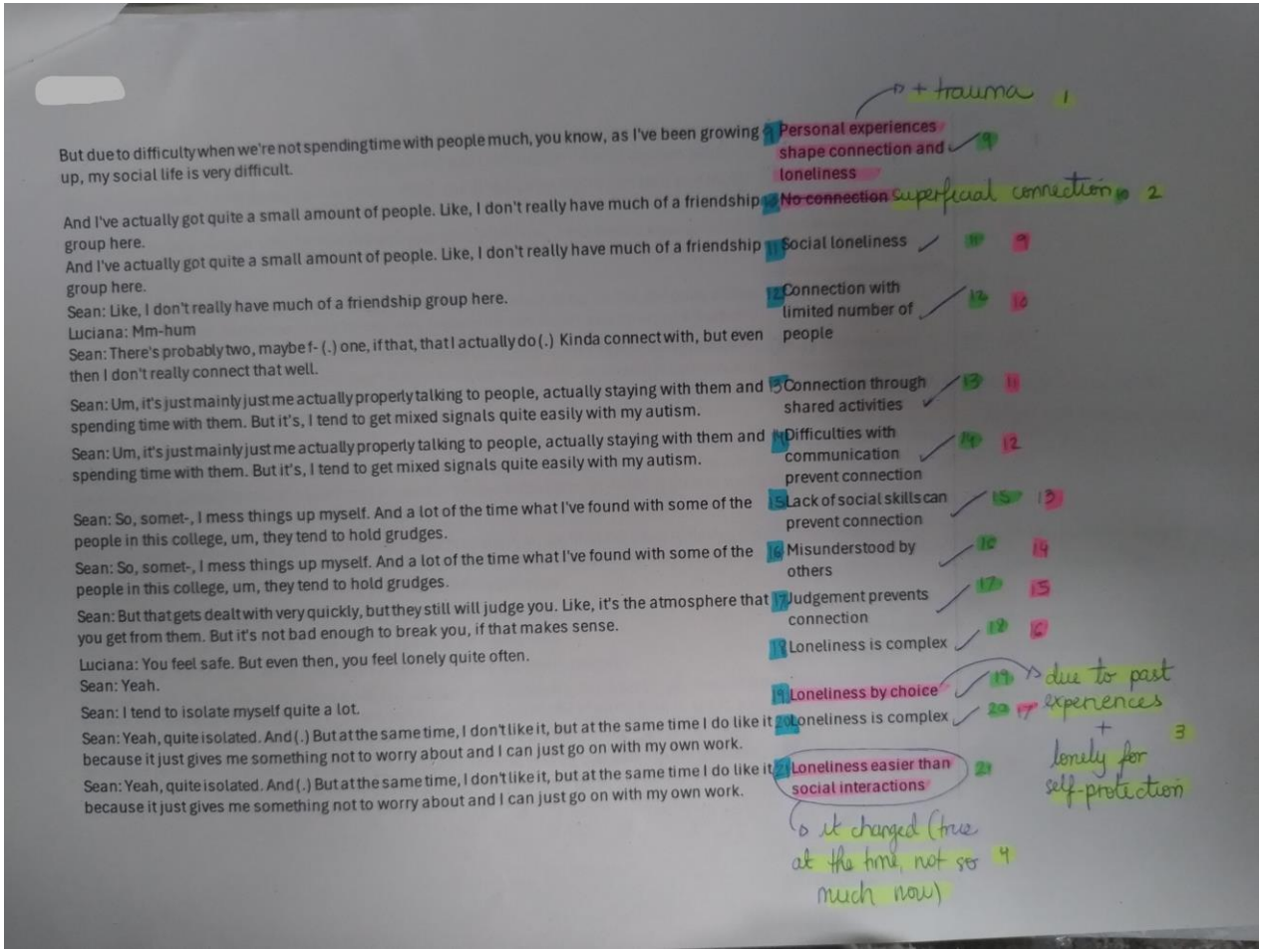


Figure 7

Example of Evaluation Sheet Annotated by Interviewer



For the second task, training consisted of a brief explanation and modelling of generation of themes by grouping codes. The demonstration showed participants how this could be done using strips of paper with the codes printed on them. New codes created during the participant's evaluation were handwritten and added to the pre-printed ones. During the demonstration, it was emphasised that there are no right or wrong answers to this process and that the main goal is to make-sense of the dataset in a way that the themes tell a coherent narrative (Byrne, 2022). This clarified to participants how generating themes is a fluid and creative process where the researcher can go through different combinations of codes, shuffling them around whilst reflecting on the different shared meanings and patterns (Braun & Clarke, 2022b; Byrne, 2022). Participants were then invited to create candidate themes (for examples, see Figures 8 and 9).

Evaluation tasks were cognitively intense. To accomplish them, participants had to first engage critically with the materials. To evaluate the codes, they were required to consider the language being used to capture the meaning of the excerpts, making sense (or not) of the code. If it did not make sense, they had to engage further trying to find a label that better described or captured the meaning of the excerpt. To create the themes, they had to think about how to combine the codes into categories that made sense to their own experiences. To avoid cognitive overload, participants were presented with 'checking points', where the interviewer offered opportunities to take a break or to end the session.

87% of codes reviewed by participants remained the same; 13% were edited or deleted. All the evaluations were considered and incorporated to the analysis during a third round of coding. It is important to clarify that the evaluation of codes through participatory data analysis did not seek judgement consistency in how codes were applied. Other forms of Thematic Analysis (TA) (for example, Boyatzis, 1998; King, 2012) are focused on inter-rater reliability. According to Braun and Clarke (2022b) the strength of coding in RTA will be

Figure 8

Example of Candidate Themes Created by One of the Participants

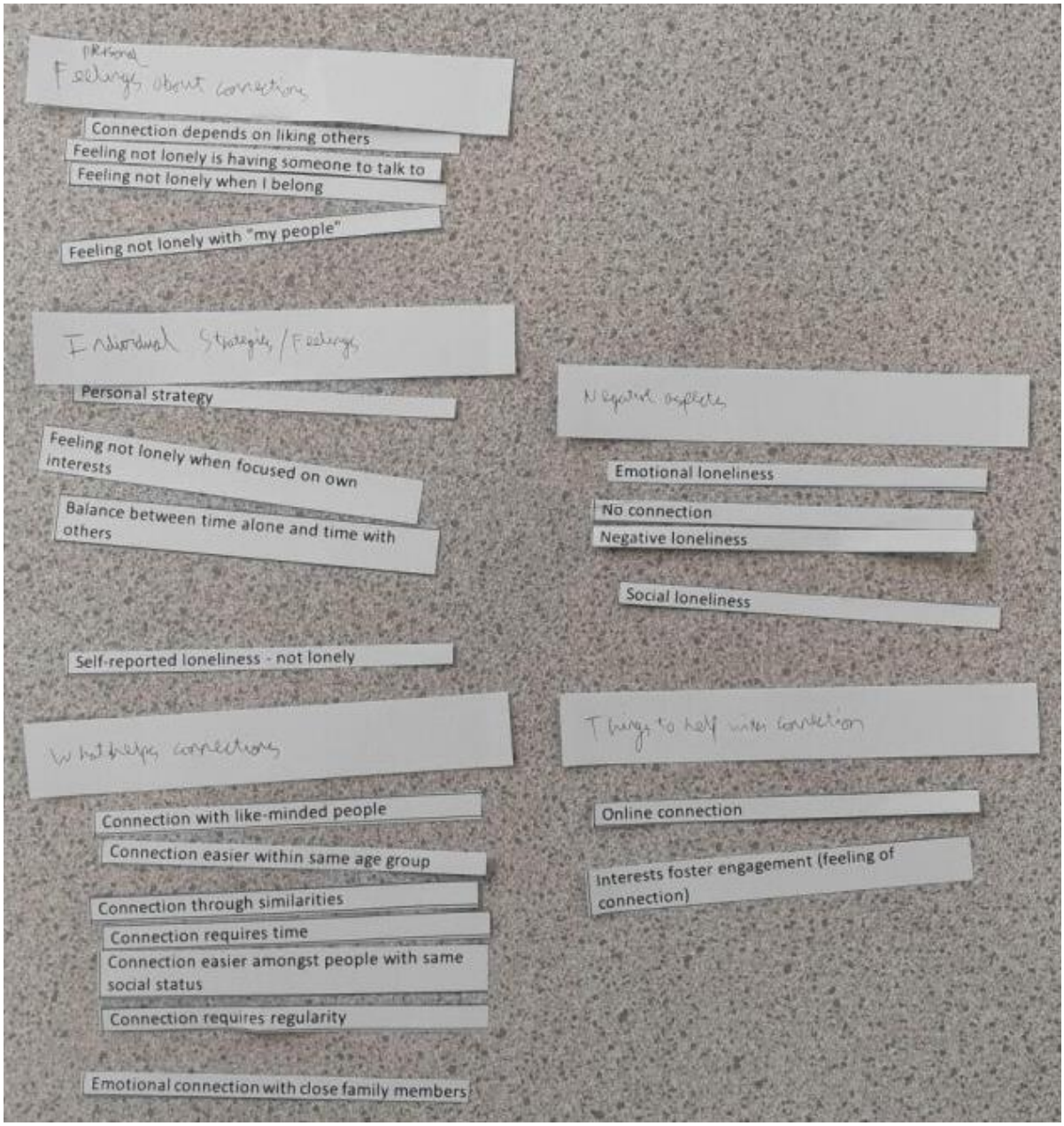
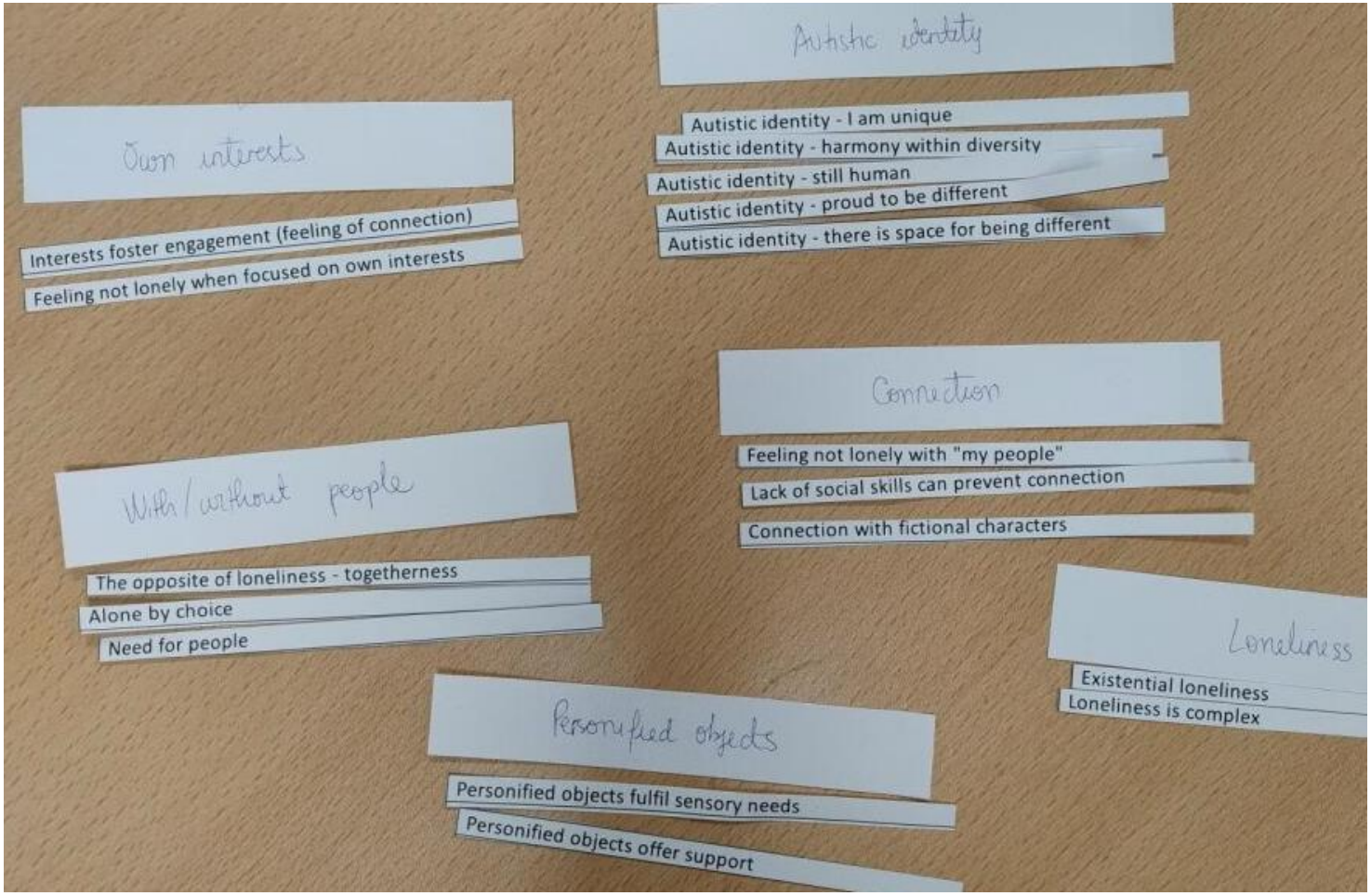


Figure 9

Example of Candidate Themes Created by One of the Participants



determined by the depth and rigour in which the researcher engages with the data. When multiple coders are involved in RTA, it is expected they will make sense of the data in different ways due to their subjectivity and positionality being unique in relation to the data. This subjectivity is not seen as a limitation that needs to be minimised as it is the case with code reliability TA, but it is considered part of the analysis and a "resource to be utilised" (Braun & Clarke, 2022b, p. 236).

Within a critical realist orientation which foresees multiple realities (Abma et al., 2019; Porpora, 2015), participatory data analysis can enrich sense making by incorporating different perspectives from key people when describing complex and subjective experiences (Abma et al., 2019). The addition of multiple views during coding highlighted contradictions and similarities in the dataset, adding nuance and complexity to the results.

Themes created by participants were not directly incorporated into the analysis. Since participants did not have access to all interview transcripts, their themes offered a partial interpretation of the data. However, the task brought awareness of how autistic young people made sense of their experiences of loneliness, and this informed the generation of themes with the whole dataset. In addition, the benefits of participatory data analysis should not be confined to researchers; rather, a defining feature of participatory research is the reciprocal exchange of knowledge between researchers and participants (Fletcher-Watson et al., 2021). Allowing time for participants to create these candidate themes gave young people a more comprehensive experience of how qualitative research is done, adding a hands-on learning opportunity to the sessions (Barke, 2025).

Generating Provisional Themes

Themes in RTA capture shared meanings across a wide range of data (Braun & Clarke, 2022a). Generating themes is a creative process where the researcher examines how

the relationships between codes might build a narrative. At the start this involves clustering codes that relate to each other by collapsing or combining multiple codes together that have meanings in common (Byrne, 2022).

For this project, this was firstly done on an Excel spreadsheet containing the excerpts of data, the first and second rounds of coding, participants' evaluations of codes and the third round of coding incorporating participants' evaluations (for an example, see Table 12). This document made the evolution of codes visible and supported the iterative process of clustering codes according to shared meanings (Byrne, 2022).

Table 12

Example of How Codes Were Clustered Together to Create Themes

Excerpt	**Round 1**	**Round 2**	**Participant's Evaluation**	**Round 3**	**Cluster**
"I could have talked to someone today" (Ben, 17)	Self-Blaming: personal responsibility for being lonely	Responsible for being lonely	Deleted code and added "connection is a two-way road", "connection requires reciprocity"	Connection requires reciprocity	Double-empathy
"I kind of feel happier when I'm lonely. I'm, like, cos it's when I'm lonely I feel like safer, kind of" (Georgia, 14)	Loneliness: is positive	Positive Loneliness	No change	Positive loneliness	Positive aspects of loneliness
"Each day is kind of different" (Joseph, 20)	Loneliness: each day is different	Conditional loneliness	Constant loneliness. Loneliness is like a backdrop.	Constant loneliness	Other types of loneliness

Once these initial clusters were formed, they were transferred to Microsoft Whiteboard where clusters of codes could be visualised and shuffled into wider sets

constituting provisional themes to be furthered explored (Braun & Clarke, 2022b). On the whiteboard overview (Figure 10) and detailed views of the board (Figure 11) it is possible to locate provisional themes (yellow boxes), provisional subthemes (pink circles) and code clusters (violet boxes). Some of the reflections that led to this initial grouping were added in the grey boxes and a record of unallocated codes was also kept on the right-hand side of the screen (below the light green box). Although themes were still underdeveloped at this stage, a few of the core ideas were already present and captured for further development. Examples include different ways of describing loneliness and the influence of stigma and normativity on how loneliness is experienced.

Figure 10

Overview of Initial Theme Development on Microsoft Whiteboard

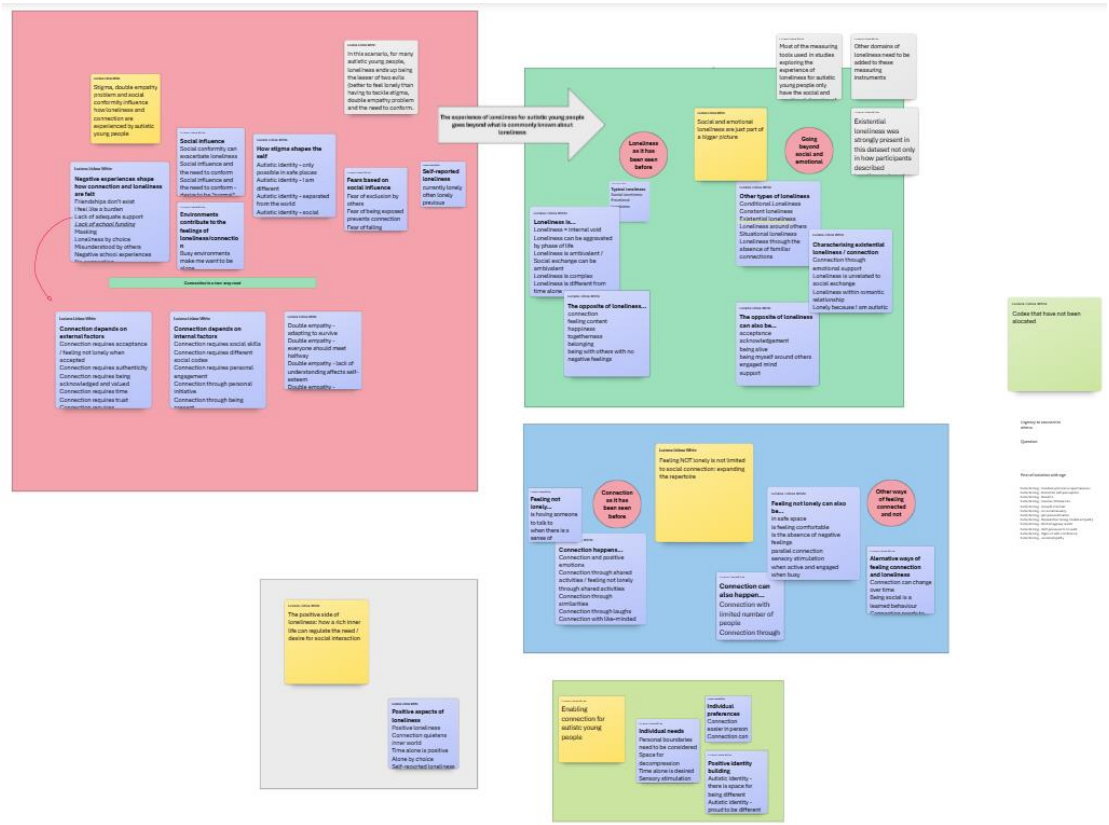
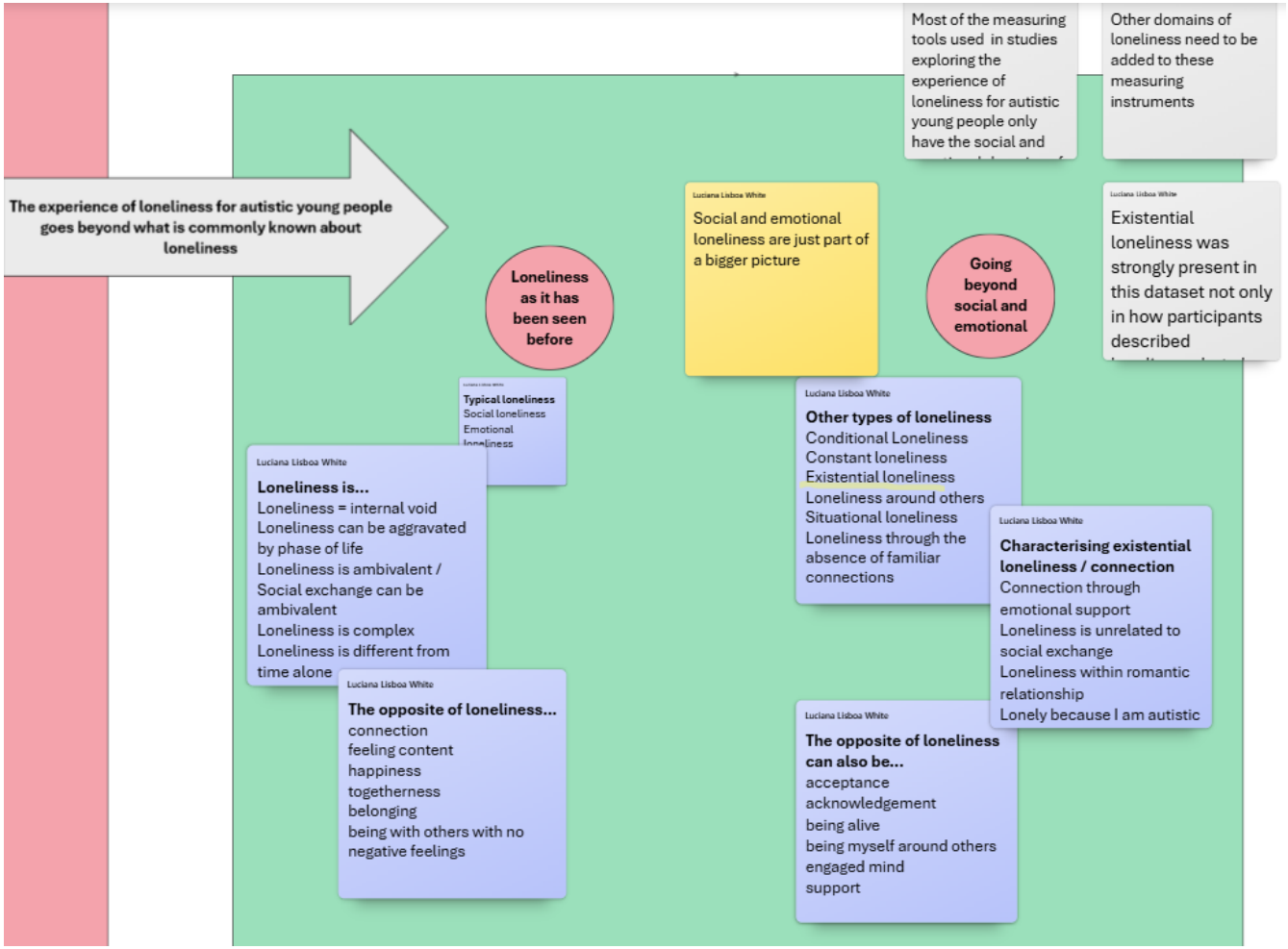
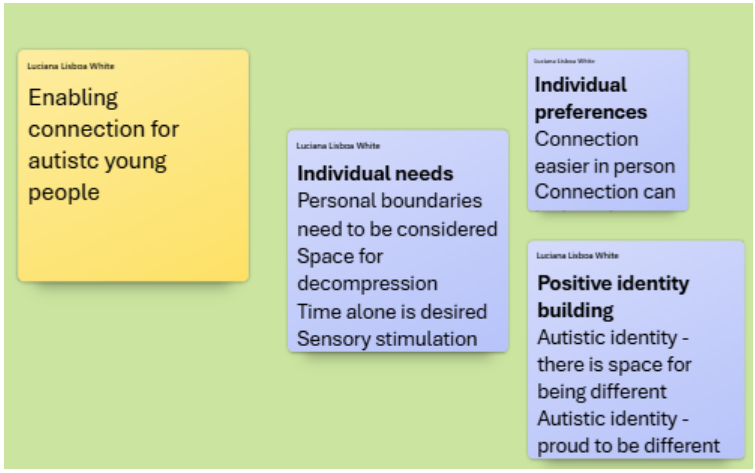


Figure 11

Selected Detailed Views of Theme Development




Luciana Lisboa White
Feeling NOT lonely is not limited to social connection: expanding the repertoire
Connection as it has been seen before
Luciana Lisboa White
Feeling not lonely...
is having someone to talk to
when there is a sense of
White
Connection happens...
Connection and positive emotions
Connection through shared activities / feeling not lonely through shared activities
Connection through similarities
Connection through laughs
Connection with like-minded
Luciana Lisboa White
Feeling not lonely can also be...
in safe space
is feeling comfortable
is the absence of negative feelings
parallel connection
sensory stimulation
when active and engaged
when busy
Other ways of feeling connected and not
Luciana Lisboa White
Connection can also happen...
Connection with limited number of people
Connection through random exchanges
Luciana Lisboa White
Alernative ways of feeling connection and loneliness
Connection can change over time
Being social is a learned behaviour


Luciana Lisboa White
Enabling connection for autistc young people
Luciana Lisboa White
Individual needs
Personal boundaries need to be considered
Space for decompression
Time alone is desired
Sensory stimulation
Individual preferences
Connection easier in person
Connection can
Luciana Lisboa White
Positive identity building
Autistic identity - there is space for being different
Autistic identity - proud to be different

At this stage, provisional themes were repeatedly reviewed in relation to the codes that supported them and in relation to how they fit within the entire dataset (Byrne, 2022). Provisional themes were reorganised and renamed into five themes that were taken to be reviewed by autistic young people: 1) Conceptualisations of loneliness from autistic perspectives: going beyond social and emotional loneliness; 2) The positive side of loneliness: how rich inner life can regulate the need/desire for social interactions; 3) Feeling not lonely and expanding the repertoire; 4) Enabling connection for autistic young people: a two-way road; and 5) The lesser of two evils: how societal issues shape how autistic young people experience loneliness and connection.

Phase 2 of Participatory Data Analysis: Evaluation of Candidate Themes

The objective of the second phase of participatory data analysis was for the autistic young people who had participated in the first phase of the analysis to evaluate coherence and relevance of each candidate theme (Abma et al., 2019). Nine participants agreed to take part.

Five candidate themes were presented randomly on A4 printed sheets (for an example, see Figure 12). Each theme was accompanied with a summary (Table 13) and illustrative quotes. Participants were asked two questions: “Do the main ideas of this theme make sense together?” and “How much are these findings true to your experiences?” Responses were given orally and by colouring-in a 10-point-bar (where 1=low and 10=high). These questions were based on guidance suggesting that candidate themes should be reviewed at two levels (Braun & Clarke, 2006; Byrne, 2022; Patton, 1990). Level one focusing on internal coherence and in how well codes inform themes. Level two focusing on how well the themes fit within the entire dataset. In this case, as participants did not have access to the whole dataset, level two focused on how well the themes fit in with their individual lived experience.

Figure 12

Example of How Provisional Themes were Presented for Evaluation



Table 13

Candidate Themes and Summary of Contents Discussed with Participants

Provisional Theme	Summary of Contents
Conceptualisations of loneliness from autistic perspectives: going beyond social and emotional loneliness	• Self-reported loneliness. • Typical loneliness • Alternative ways of feeling loneliness. • Existential and experiential loneliness.
The positive side of loneliness: how a rich inner life can regulate the need/desire for social interactions	• Loneliness is ambivalent. • Loneliness can be positive.
Feeling not lonely and expanding the repertoire	• Alternative ways of feeling NOT lonely. • Alternative ways of feeling connected.
Enabling connection for autistic young people: a two-way road	• Internal mechanisms and personal characteristics that hinder/facilitate connection with others. • Closing the gap between the neurotypical and the neurodiverse worlds. • Society meeting autistic people half-way (accommodating needs). • Improvement of wellbeing through spaces and support for authenticity and positive identity building.
The lesser of two evils: how society issues shape autistic young people's experiences of loneliness and connection	• How negative experiences can shape feelings of loneliness and connection. • How social influence and peer pressure can have a negative effect on how autistic young people connect to others. • How social stigma affects relationships and identity building.

Not all participants evaluated all themes as sessions were designed to avoid cognitive overload. Overall, candidate themes received five to eight evaluations each. On average they were considered 87% internally coherent and 77% relevant to personal experiences. An example of participants' contributions was when two participants (Charlie, 18 and Bethany, 14) evaluated the theme "Feeling not lonely and expanding the repertoire". Whilst Charlie said that alternative ways of connecting could sometimes "exacerbate feelings of loneliness" Bethany said, "This is very true to my experience. I can just watch telly and not need anything else".

These evaluations of candidate themes informed the final stage of the analysis. Despite many agreeing that the candidate themes were relevant and coherent, contradictory views, such as the ones from Charlie and Bethany, contributed richer and more nuanced insights for the analysis (Braun & Clarke, 2022b), and to the further refinement of the themes.

Finalising Themes

The second phase of participatory data analysis was useful in establishing internal coherence of the provisional themes. At this point, to complete the analysis, a visual map was produced (Figure 13). This was useful to have the candidate themes and the data that supported them in one working document, without the clutter of the codes. The map helped the visualisation of possible connections between themes and relationships with subthemes (Braun & Clarke, 2022b; Byrne, 2022).

The blue circles represented the candidate themes, supported by clusters of codes in the green boxes. The yellow boxes contained interpretations and suggested directions through which the data could be framed. The lines represented different kind of relationships between the items (Braun & Clarke, 2022b). Blue arrows represented strong relationships, green lines

represented supporting relationships, whilst green dotted lines represented relationships to be further explored.

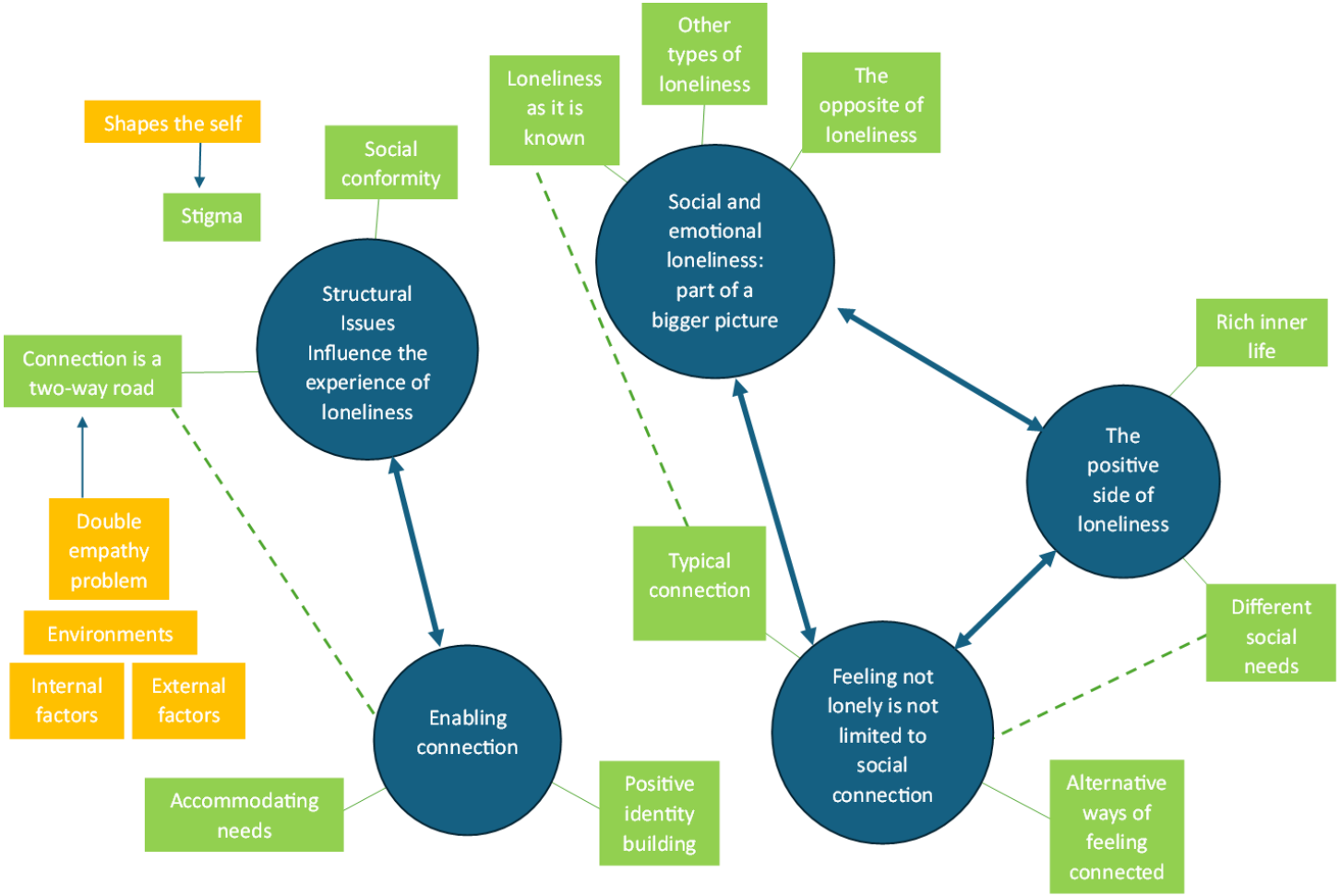
Working with the map involved going backwards and forwards, evaluating how meanings could fit within the whole of the dataset to create a coherent narrative. Several times, codes were revisited and discussions with supervisors supported reflection on different patterns across the dataset and relationships between themes.

The refinement of the map led to the candidate themes being renamed and reorganised. The creation of two overarching categories organised the themes according to two recurring patterns. The first focused on descriptions of loneliness and offered a new conceptualisation of loneliness from autistic perspectives. Here, an extra theme was created (Theme 4) to separate aspects of social and emotional loneliness that are compatible with traditional views, from alternative ways that loneliness is experienced by autistic young people. The second overarching theme focused on systemic issues that can influence experiences of loneliness and connection for autistic young people. The contents of each theme and illustrative quotes are explored in more detail in the following section.

Please note that the extracts from interviews have been identified with pseudonyms except from Bethany who explicitly asked for attribution. Anonymous extracts are contributions from the wall of thoughts.

Figure 13

Visual Map of Provisional Themes

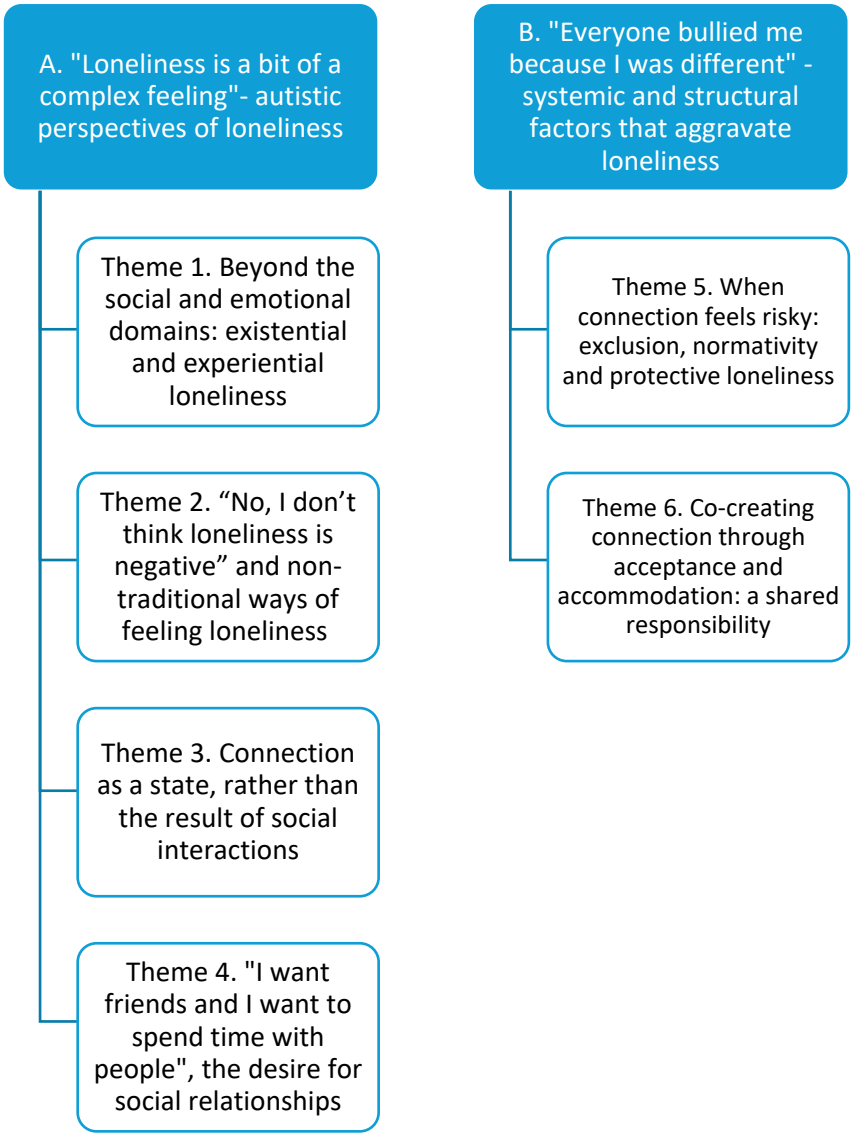


Results

Six subthemes were organised under two overarching themes (Figure 14).

Figure 14

Themes of Loneliness and Connection as Described by Autistic Young People



The first overarching theme, "*Loneliness is a bit of a complex feeling": autistic perspectives of loneliness,* expands what is known about loneliness by, a) going beyond social and emotional domains; b) understanding non-traditional ways of feeling loneliness; c) acknowledging connection as a state rather than reducing it to social interactions; and d)

exploring autistic young people's desire for social relationships. This overarching theme collects all the descriptions of loneliness and connection contributed by participants, helping to reconceptualise loneliness from autistic perspectives. The second overarching theme, *"Everyone bullied me because I was different": systemic and structural factors that aggravate loneliness,* explores how a) exclusion and normativity can shape experiences of loneliness and connection for autistic young people and b) how connection can be co-created by accommodating environments. This overarching theme moves beyond individual experiences and inner perspectives to explore the complexity of the experiences of loneliness in relational contexts. Although loneliness is felt by the individual, this overarching theme highlights how it can be built and influenced by collective behaviours.

A) "Loneliness Is a Bit of a Complex Feeling": Autistic Perspectives of Loneliness

Theme 1. Beyond the Social and Emotional Domains: Existential and Experiential Loneliness

For these autistic young people, loneliness could be unrelated to being socially satisfied. Participants added tiers to the experience of loneliness which were identified as existential and experiential loneliness during the deductive phase of coding. Existential loneliness could be felt as a backdrop in autistic young people's lives, rather than a response to social situations – a constant presence that permeated all kinds of experiences, "I feel lonely most of the time, even when I have no reason to" (anonymous post). Participants said they felt lonely "always… even now, throughout years of my life" (Tony, 17), at college, less so at home, but "everywhere" (Joseph, 20), "even when there's people there" (Ashleigh, 19) and when their lives were "full of people," (Tony, 17).

Loneliness was described as a feeling of being detached from the collective. For James (17), loneliness related to feeling different and unable to "naturally" fit in like other young people do,

> *It was mainly just like a feeling of not feeling normal, kind of feeling. Because you're like, everyone else can just have a good natural whatever. Why am I not capable of that really?* (James, 17)

Being autistic or displaying autistic characteristics were described by some as the reason why they feel different and unable to join peer groups. Bethany (14) said she feels lonely because she 'can't read' other people or their facial expressions, "So, I have no clue what's going on". John (20) said he attended a different college from his high school peers because he is autistic,

> *I miss being with people that are from my [previous] high school. It's because they're not autistic and it's only I am. That's why I'm, I'm in one college on me own.* (John, 20)

Being different was also perceived as a reason for not being liked by others and for being excluded, "I wasn't really aware how much people didn't like me. But I think looking back, they definitely were judging" (Esther, 18); "There were a few people in our group that just did not like me. And I tried so hard to get them to like me and I was always nice" (Indiana, 17).

Richard's (18) artwork (Figure 15) and description of it illustrate how he often feels removed from the world. He portrayed a lack of fit between who he is and the world around him, "Well, what I did was (pause) I coloured myself to separate myself from the background because I, I've got my own colours, but everything around me just doesn't (pause) fit me".

Figure 15

Richard's Artwork Illustrating Loneliness Beyond Social and Emotional Domains



Experiential loneliness reflected a sense that personal experiences remained inaccessible to others. Unlike emotional loneliness, it was rooted not in a lack of closeness, but in feeling fundamentally misunderstood. Participants described this type of loneliness when their experiences were misaligned with what is considered conventional or universal,

> *It feels like I am the only person there, and I have all these thoughts and feelings like nobody will ever understand me, and nobody will ever understand what it's like to be me, nobody will listen to me.* (Tony, 17)

Ashleigh (19) explained how her requests for accommodations have sometimes been ignored and how this contributed to feelings of loneliness, “It’s just not working and that makes me feel even more lonely”. Having her needs overlooked extended beyond the frustration with individual interactions and reflected a broader sense that her perspective remained inaccessible to others, “That makes me feel like I've got nobody that will actually ever understand” (Ashleigh, 19). Limited understanding of autistic experiences left some feeling unseen within social environments. For Esther (18), feeling lonely was associated with feeling “almost like I didn't exist”, suggesting that loneliness emerged from feelings of being unacknowledged by others.

In summary, this theme captured descriptions of loneliness that transcend the way loneliness has been commonly described. Experiences of loneliness described by participants included feeling fundamentally separated from the world (existential loneliness) and feeling that subjective experiences of being autistic cannot be understood or shared by other (experiential loneliness). These feelings are different from and can co-exist with feelings of (un)fulfilling social relationships (social and emotional loneliness).

Theme 2. "No, I Don't Think Loneliness Is Negative" and Non-Traditional Ways of Feeling Loneliness

This theme captured alternative ways in which loneliness has been experienced by this group of young people. Loneliness was not consistently recognised as a negative experience, challenging more traditional conceptualisations and adding nuance and complexity to its understanding.

When asked about emotions, loneliness was not always recognisable or easy to describe. John (20) said that loneliness is a negative feeling but could not name emotions associated with it. Asheleigh (19) struggled to name emotions associated with loneliness but said she can feel it in her body, "physically, it feels like I can feel my heart just drop. And it feels like this pit in my heart. Or it even feels like my stomach's like empty. And I feel like I'm about to throw up." Similarly, Qamri (23) described having physical responses to feelings of loneliness, "I was crying and throwing up a lot". In contrast, for Indiana (17) loneliness was never "an all-encompassing feeling", rather, it was more of a new and learned behaviour that came with the realisation that having friends could be a positive experience. They reported that their younger years were "completely free" from feelings of loneliness, "I was just absolutely chill being on my own, and then I found friends and I was like, 'oh, this is kind of cool actually'".

Although some participants named emotions that are commonly associated with loneliness, such as "sadness, isolation" (Charlie, 17) and "sadness and anger" (Parker, 17), others associated feelings of loneliness to boredom, including Max (12) and Adam (17), "I feel like dealing with other people is (pause) is not very fun. But dealing with nobody at all is really boring" (Adam, 17). Loneliness also led to ambivalent emotions and Manisha (17) described it as being "bored and happy at the same time". This ambivalence was also recognised by Sean (23), Georgia and James (17), "I would say loneliness comes with both

sides really" (James, 17). In addition, Kass (13) said, "No, I don't think loneliness is negative".

The positive side of being lonely appeared to come from being free from social demands. An absence of relationships, although challenging, seemed to create opportunities to focus on their own interests or self-improvement. Some of the young people described finding the fuel to improve their abilities or pursue hobbies. Alex (15) said that when he is drawing, he thinks about how lonely he is, but these thoughts made him better at his craft, "I mean, they do [thoughts about loneliness come to mind], but it usually makes my drawings a lot more interesting than they are". James (17) said that without having to worry about social interactions he had more time to practise on his musical instruments,

> *So, there is the part of, because I didn't have to worry about any time spent socially at all, it meant I could just work. It means I could just practise on my instruments, and it meant ultimately, I could just basically be very good at what I did, essentially.*

In summary, loneliness has been recognised by this group of autistic young people mostly, but not consistently as a negative experience. Some have talked about the positive side of loneliness. This ambivalence illustrates the complexity of the construct. For some, loneliness was associated with fewer worries relating to social demands, allowing more space to be creative or to be involved with activities they enjoyed, despite the ongoing need to belong. This was conceptualised as positive loneliness.

Theme 3. Connection as a State Rather Than the Result of Social Interactions

This theme captured how feeling connected can emerge through experiences of presence, immersion, familiarity and authenticity, rather than social interactions. Feeling 'not lonely' was often understood as reducing emotional distress through experiences that fostered comfort, absorption, authenticity or quiet companionship, instead of focusing on increasing

social interactions, “For me, the opposite of feeling lonely is when I’m like with somebody, and I’m feeling absolutely nothing negative” (Ashleigh, 19). Many autistic young people reported feeling ‘not lonely’ – or there being less need for social relationships – when engaged in personal interests,

> *LLW: When you’re focused on these activities [personal interests], do you ever feel lonely? Do you ever feel the need for people?*
>
> *Evelyn: Umm, no, I wouldn't say so, not at all. I mean, it’s just kind of like a whole new space, um, like getting so focused and like in my own mind.”* (Evelyn, 15)

Connection through immersion was described as being involved with personal interests such as being active, cycling or walking. Participants also mentioned reading, writing, creating stories, playing a musical instrument, playing video games, role playing, model making, scrapbooking, travel planning, listening to music, painting, or dressmaking. For example, for Joseph (20) “even just doing something active” is enough for him not feeling lonely. Georgia (14) also reported not feeling lonely when listening to music, playing the piano, being in her safe corner, or being with her cats or plants.

Other immersive strategies used to ease negative feelings of loneliness included positive self-talk, “I guess I talked to myself” (Esther, 18). Other participants described having a rich inner life, including experiences with lucid dreaming, daydreaming, and visual activity in their minds. They reported not missing people when involved in these activities and being content on their own, “Again, I don’t feel lonely all that often. Sometimes I’m just really happy in my own company” (Indiana, 17). Georgia (15) also talked about immersing herself in different imaginary scenarios and not desiring social interactions when doing so, while Max (12) described using his imagination to create people when feeling bored or lonely and felt positive about his ability to be immersed in his imagination, “I use my imagination a

lot". Similarly, Richard (17) reported creating imaginary realities, "Every time I feel lonely, I just think of anything that goes in my head. I have a really strong imagination" and described daydreaming as promoting wellbeing. For these young people, being lonely created an opportunity to engage with rich inner worlds. Having a creative and active inner world also appeared to influence the need for fewer relationships and to promote positive loneliness where autistic young people thrived in their interests. Some participants were clear in their preference for alternative types of connection over social connection, "I don't think happiness comes from people. I think it comes (pause) from your hobbies and things like that" (Kass, 13).

'Connection through shared presence' was described in terms of having parallel interactions, such as observing another person or enjoying silent companionship. Parallel connections were mentioned as listening to friends having a conversation, watching others playing video games, listening to people going about their day, or quietly sitting next to a family member who is busy with an activity, "Just being able to, like, hear people doing their own thing, this makes me feel less lonely" (Ashleigh, 19).

Participants also mentioned feeling 'not lonely' in relationships with fictional characters which provided a sense of connection without the social demands. This included connection with characters in video games, TV shows, movies or books, and with objects such as teddy bears or toys was described by some young people as being enough for them to feel fulfilled, "I want to say most of the characters (pause) I can relate to in ways besides loneliness and stuff" (Ben, 17). At the same time, Qamri (23) described fictional connections as being only distractions for when she is feeling lonely and not enough to replace a desire for being with other people. Similarly, Charlie (18) said that alternative ways of connecting, such as connecting with fictional characters in videogames, could sometimes "exacerbate

feelings of loneliness" as it becomes clear for them, they are alone when engaging in these activities.

Connection with nature and pets were mentioned by some as safe and non-judgemental forms of companionship. Interactions with pets were described as offering space for authenticity, "They definitely don't judge you" (James, 17). Some autistic people saw pets as good substitutes for human relationships and felt the need to be with people less when interacting with them, "I just need the cat and I'll be fine" (Parker, 17). Other participants said they would still need human friends, despite pets being mentioned as a valuable support when lonely, "[Pets were important] particularly back in my younger years. Obviously, they're a massive part, and they're very important to me still, but not as much as the group [of friends]" (James, 17).

Connections with reduced or predictable social demands, like friendships with a selected group of people appeared to help participants to prevent stress related to social interactions. For example, Georgia (15) shared her interests with only a few people, "I only show a few people my plants and that". James (17) said, "I'm very careful in who I choose to be my friendship group because I'd never ever want to get dragged down into any sort of chaos which is caused by who I'm around". Laura (17) said the opposite of being lonely is, "being with a small group of friends. Not big 'cos then I just kind of tend to get left out. But when it's like a small group of friends. Usually specific people".

This theme described ways in which participants felt 'not lonely' through experiences that promoted presence, familiarity, immersion and authenticity. Rather than understanding connection as inherently social, the evidence suggests that the opposite of loneliness is meaningful connection, which may or may not involve other people.

Theme 4. "I Want Friends, and I Want to Spend Time with People", the Desire for Social Relationships

This theme was associated with unfulfilled social needs and descriptions of loneliness that are more closely aligned with how social and emotional loneliness are described.

Loneliness was most frequently described as complex, negative and related to the absence of others, "Well, loneliness is the thing where you don't really talk to people and you just sit there doing nothing" (Max, 12). Participants reported feeling lonely when they did not have anyone to talk to, illustrated by the anonymous drawing of the virtual wall of thoughts (Figure 16) and when they were unsatisfied with their social network, "I didn't really have anyone to talk to at all. Still now, I don't have any friends" (Alex, 15), reflecting social loneliness. They also described loneliness as being unhappy with the quality of their relationships or when they desired more closeness, "Well, I felt like I was (pause) by myself. Like physically, but also emotionally, like there wasn't anyone there for me, almost" (Jacob, 17), characterising emotional loneliness.

Figure 16

Anonymous Drawing Illustrating "I Want Friends, and I Want to Spend Time with People", the Desire for Social Relationships



Some autistic young people described their desire for social interactions, particularly a wish to talk to and spend time with others explaining that this would contribute to feelings of belonging, “Well, to be honest, I want friends and I want to spend time with people” (Sean, 23); “Sometimes, I do genuinely just wanna talk to people as well” (Indiana, 17). These quotes demonstrate that participants valued social connections and expressed a desire for friendships, consistent with traditional conceptualisations of social and emotional loneliness.

In this theme, the descriptions of loneliness offered by autistic young people were aligned with more familiar understandings of loneliness. They reported having unfulfilled expectations related to the number or quality of their social relationships, showing that many desired social connections and missed having more of it.

B) "Everyone Bullied Me Because I Was Different": Systemic and Structural Factors that Aggravate Loneliness

Theme 5. When Connection Feels Risky: Exclusion, Normativity and Protective Loneliness

This theme captured how persistent negative social experiences and neuronormative expectations shape autistic young people’s experiences of loneliness and connection.

Narratives offered by some participants showed that experiences of being socially excluded and bullied for being different are common, “Everyone bullied me because I was different” (Parker, 17). These experiences shaped later relationships, leading some to view others negatively or as untrustworthy, “You do sometimes start to think very, very negatively of people” (Sean, 23); “Real friendships, they don’t exist” (Alex 15). Many autistic young people described accepting or choosing loneliness over relationships that failed to recognise or accommodate their needs, “I chose to be lonely because I couldn’t handle other people” (Adam, 17). Participants described fear of being exposed, excluded, or failing to deliver

'typical' social behaviours when engaging in social contact and said loneliness was sometimes easier to endure,

> *...it's like being alone is the worst thing imaginable, but right now in this moment, after the horrible things that have happened today, it might be the best thing to do.* (Tony, 17)

Aligned with Tony's (17) framing of loneliness as a protective response in moments of distress, Georgia (15) also described being "safer" when lonely.

Alex (15) who described suffering exclusion and bullying by his peers shared how these experiences have influenced the way he navigated social relationships over the years, and made him socially cautious,

> *I usually see people who pretend to be my friend and suddenly, you know, trick me, which is why I'm a lot more careful of what, who, if I choose anyone to be my friend. And so far, unfortunately I've not found anyone who I can really trust at least in, at least at my age.*

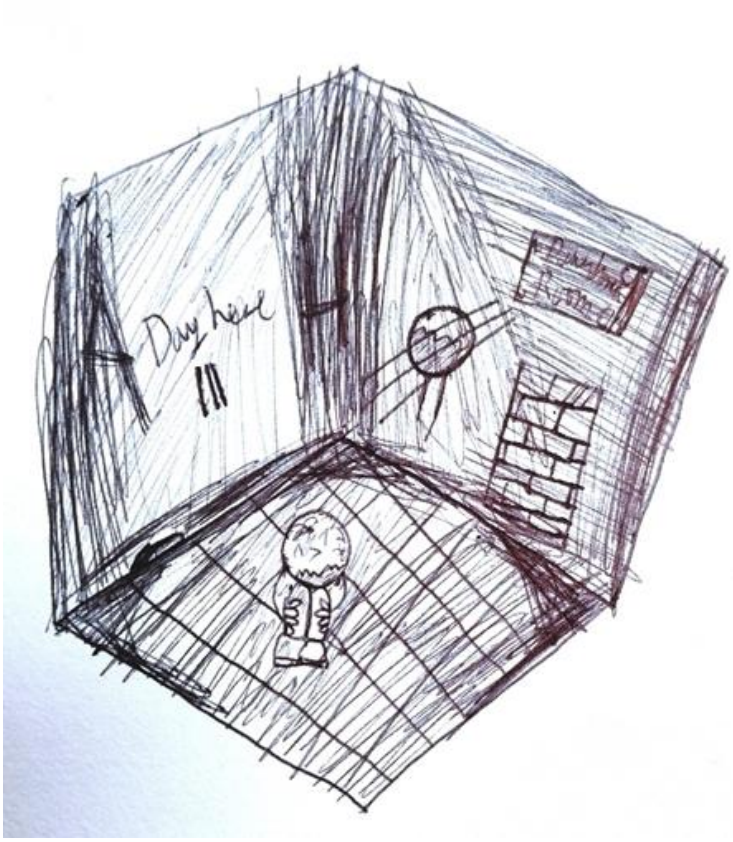
Parker (17) said they adopted self-protective approaches such as hiding their emotions to avoid being hurt again, "I do put a more happier like personality when I'm out".

Failing to meet neuronormative expectations made participants feel responsible for their loneliness, "I'm not very good at actually, um, socialising with people properly" (Sean, 23); "I've never really been able to [connect to people]" (Charlie, 17); "I don't feel like I've done enough to keep a lot of connections" (Adam, 17). This sense of responsibility made loneliness feel like a punishment for failing to meet expectations. Alex (14) visualised loneliness (Figure 17) as repeated rejection and isolation that made him feel trapped, "It feels like you're in a cell". He described his drawing as a "box like room, very small" where the character felt locked in. The doorway was "bricked up" and there was a sign that said,

"Punishment room", "Feels like you're being punished for every time you're stuck being alone" (Alex, 15).

Figure 17

Alex's Artwork Illustrating how Normativity Can Shape Experiences of Loneliness and Connection



Personal characteristics that made it difficult to conform to neurotypical expectations of social behaviour were identified as contributing to loneliness, "I tend to get mixed signals quite easily with my autism". Some participants shared that anxiety, and mental ill health can make them nervous to engage in social activities, "I don't like going outside really because I get too nervous about (pause) going outside and seeing people"; "It's a mix of my anxiety and depression. I just close myself off. And I don't really like opening up," (Parker, 17).

In contrast, participants who felt they possessed 'typical' social skills described feeling less lonely. Indiana (17) described finding it easy to make new connections despite displaying behaviours that might be seen as odd, "I think I'm pretty good at being social. I'm (pause) awkward obviously sometimes, but I generally know how to socialise". James (17) said working on his social skills improved his social experiences, by talking less about music,

> *As with most autistic people, I have my special thing, music in my case. But in my early days of secondary, I wouldn't shut up about it, which didn't help very much. I was rubbish in general conversation, obviously much better now.* (James, 17)

Showing personal engagement and initiative was mentioned by Parker (17) as strategies used when he wants to socialise, "Well, (pause) I'm not wearing my headset for one (chuckles). And (pause) I try to start up conversations with people". By adapting communication styles and adopting 'typical' ways of socialising, James and Parker felt social interactions became easier, illustrating how participants viewed connection as partly dependent on their own efforts and on meeting neurotypical expectations.

Pressure to display 'typical' social behaviours and having a lower need for social relationships when compared to what is normally expected were mentioned by participants as things that make them feel different and more lonely. They felt uncomfortable being seen on their own. Laura (17) said that being alone does not make her feel lonely but being alone in front of others can cause feelings of loneliness, "When I'm alone, I don't feel lonely then, but when I'm alone in front of other people, then I feel very lonely". Charlie (17) felt lonely when sitting on her own during lunch and said these feelings were amplified by her loneliness being obvious to others, "I usually sit at a table by myself, and then it (pause) as well as

feeling lonely, I look really lonely as well". For these autistic young people, appearing lonely to others could feel more difficult to manage than loneliness itself.

This theme summarised how repeated negative social experiences and neurotypical expectations could contribute to autistic young people's feelings of loneliness. Some young people described choosing loneliness as an alternative to difficulties caused by social interactions. In addition, dominant expectations surrounding social connection appeared to influence how autistic young people perceived themselves and evaluated their own ways of feeling connected to others.

Theme 6. Co-creating Connection Through Acceptance and Accommodation: a Shared Responsibility

This theme illustrates how autistic young people's experiences of connection were shaped by whether they felt accepted, understood and able to be authentic, going beyond social and emotional loneliness. The accounts suggest that existential and experiential loneliness may be reduced when needs are recognised and accommodated.

Participants described how accommodating environments fostered self-regulation, which in turn made feelings of connection easier, "In my old school they had, um, a quiet room, and I liked being in there, cos it was lonely, but in a nice way" (Kass, 13); "I think I like the silence" (John, 20). The quiet room described by Kass and the silence described by John are restorative, whilst the school corridors were experienced adversely, "I don't miss being pushed around in hallways" (Kass, 13). Evelyn (15) had a similar experience suggesting that hostile environments make sustaining friendships or engaging socially difficult. She felt her everyday needs were not met, and she struggled to manage the school environment and the complexity of social relationships, "having to navigate that every day and, like, the sensory things and the friendships just became difficult".

In contrast, Jacob (17) mentioned how he can feel connected when there is reciprocity and acceptance, “When you’ve found your people, the group that you fit in with, then you feel very welcome, you feel involved, you feel like people actually want you to be there”. Similarly, Parker (17) mentioned the positive side of being part of groups that offer a sense of community, “It makes me feel happy, like I’m somewhere where I belong”. An anonymous post on the wall of thoughts said that connection is felt when “people want me to be with them”, demonstrating the importance of reciprocity to fostering feelings of connection and belonging. James (17), who described being not lonely at the time of interview, explained that being amongst like-minded people allowed him to be accepted,

> *I’ll say, when you’ve got people who are like-minded, I feel here [at present school] like I am genuinely accepted just for who I am. Whereas in [name of previous school], I think I had to put on a bit of a persona and appear more normal than I am, if that makes any sense.*

Being acknowledged and valued were mentioned as essential for connecting with others. Joseph (20) expressed how important it is to be seen by his peers. He feels he can connect with them when he can feel their empathy, “I want people to know I actually exist, I’m not, just because 90% of the time I don’t look like I’m struggling, I am struggling”. Trust, understanding, and warmth were also mentioned as important elements that contribute to social connection. Richard (18) said he did not feel lonely at college due to having a network of people who seemed to care for him, “[Lonely] At college? Not really because like there's people here, I can actually talk to, and they've told me loads and loads of times I can talk to them”.

Family and friends were also mentioned as a source of support, “If I feel upset or anxious, then I can count on my friends, and they don’t judge me for it (Qamri, 23); “My

family are absolutely brilliant. If I didn't have my family, I don't know quite where I'd be" (James, 17). In contrast, when participants felt their authentic selves being judged by others, they related difficulties to establish relationships, "Cos it's hard to go out and, you know, actually meet people because people, when you meet them, they assume you're weird or you're rude (pause) and that you're just not like them" (Parker, 17).

Participants mentioned that time alone is often appreciated and desired and that a balance between being alone and with others is needed, "You crave a little bit of attention, but then you don't always want too much of it" (Sean, 23). Part of this balance could be allowing time and space for decompression after sessions of intense social demands, such as a full day at school. These were experienced as necessary rather than reflecting social withdrawal or loneliness and some participants felt these needs were recognised and supported by others, which meant their environments were free from neuronormative social expectations, "When I get home from school, I go straight up to my room, and then for like a few hours, I'll be there, and then I'll come downstairs" (Georgia, 14);

> *I usually, erm, like to stay in my room where I have all my things. Especially after college, it's just where I go because everything's like quieter there and all the noise that kind of builds up. It's just the quietest room in the house.* (Charlie, 17)

Participants who reported less loneliness described being authentic and accepted by people and environments who valued difference. One participant posted on the virtual wall of thoughts that connection is related to being able to be authentic and safe at the same time. They completed the prompt "Connection feels" with the anonymous post: "...like I have a safe space where I feel less tense and more comfortable a space where I feel I can be myself".

Bethany (14), who did not feel lonely, painted herself as a red rose amongst blue roses (Figure 18). When asked whether she wanted to be like the blue roses she replied, "No, I'm

happy being this one". Rather than reflecting only individual resilience, Bethany's account illustrates how being supported to embrace her autistic identity enabled her to experience difference without feeling isolated or excluded. She belongs as the red rose.

This final theme showed that reducing loneliness involves more than improving social skills or increasing social opportunities. Recognising and accommodating autistic ways of communicating, relating and regulating can contribute to feelings of belonging and less existential and experiential loneliness. The evidence outlined suitability of environments, provision of adequate support and acceptance. These were described as underpinning conditions for autistic young people to express authenticity and to feel they belong.

Figure 18

Bethany Stockdale's Artwork Illustrating How Acceptance Fosters Feelings of Belonging



Discussion

This participatory study used flexible and creative methods to understand experiences of loneliness and connection for a group of autistic young people. The results expand the concept of loneliness by adding autistic perspectives and by showing how autistic young people's experiences may include forms of loneliness that are not adequately captured by traditional social and emotional definitions. The findings suggest that loneliness may be multidimensional, ambivalent, and shaped by the relationship between individuals and their social environments.

The findings of the present study agree with previous research that understands loneliness as multidimensional (van Tilburg, 2021; Korzhina et al., 2022). Loneliness was defined beyond social and emotional domains (Weiss, 1973). Loneliness appeared in some descriptions as being constant and independent from an individual's satisfaction with their social relationships. These descriptions included feeling lonely in social environments. These feelings of loneliness were understood as disconnection from others that comes from being invalidated and excluded from the world. This was identified as existential loneliness.

Existential loneliness has been defined as the awareness of oneself as an isolated individual (Ettema et al., 2010; Yalom, 2020) or as an ever-present absence of relatedness (Ettema et al., 2010). It includes experiences of not being understood at a deep, authentic level (Bolmsjö et al., 2019). It is felt when people feel fundamentally separated and alone in the world, despite having others around (Larsson et al., 2019). In summary, existential loneliness is a deep form of loneliness, that involves a sense of profound disconnection often related to feeling different or misunderstood by others (McKenna-Plumley et al., 2023). In this study existential loneliness was described as feelings of being an outlier, odd, or irregular. A lack of identification from others and with others. Young people's narratives showed that feeling different from everyone else and not 'fitting in' could generate feelings

of existential loneliness. This type of loneliness can create a perception of being detached from the social fabric or of not pertaining to this world. And when their loneliness was seen by other people and judged negatively, these young people felt lonelier.

Another dimension of loneliness described by autistic young people was experiential loneliness – a subjective state that is not shared or understood by others (Stein & Solomon, 2017). This can be felt as being alone with one's experiences. Experiential loneliness came from being without common ground with peers, or when lived experiences were not acknowledged by other people. It includes feelings of non-belonging when life experiences are perceived to be different from what is considered 'ordinary' or 'typical'. This appeared mainly in descriptions that involved individual needs being ignored or not accommodated by people. Recent research on the experiences of loneliness for autistic adults found that the lack of societal understanding and acceptance of autism not only hindered connection but also contributed to feelings of loneliness (Grace et al., 2025).

The inclusion of these domains of loneliness in understanding autistic young people's experiences supports previous research that emphasises the complexity of loneliness (Cacioppo et al., 2015; Ernst & Cacioppo, 1999; Motta, 2021; Schmidt, 2023) and the challenges of defining and measuring it (Maes et al., 2022; Morrison & Smith, 2017; van Tilburg, 2021). A growing body of research has adopted a multidimensional approach when investigating experiences of loneliness for different groups of people (Gedvilaitė-Kordušienė, 2017; Hadeei, 2024; Korzhina et al., 2022; Stein & Solomon, 2017). Yet, the systematic review that preceded this study, showed investigations of experiences of loneliness for autistic young people have been limited to social and emotional domains. Besides, they have consistently used standardised loneliness scales that do not represent autistic phenomenology (Lisboa White et al., 2024).

Although existential, experiential, social and emotional loneliness have overlapping emotions, such as emptiness, abandonment, and isolation (van Tilburg, 2021), this intersection can lead to different forms of loneliness being treated as equivalent. By narrowing investigations of loneliness for autistic young people to a 'typical' experience, for example, the absence of inadequacy of social relationships, autistic experiences of being fundamentally different and misunderstood are not legitimised (Milton, 2012; Whitehead, 2023). Besides ignoring feelings of existential and experiential loneliness, guidance informed by this reductionist approach could inadvertently support interventions such as social skills training with the intention of changing autistic behaviours to suit normalised views of connection (Hull et al., 2024).

The findings from this study support the notion that results are not always comparable for autistic and non-autistic people (Caruana et al., 2021; Cassidy et al., 2018a; Cassidy et al., 2018b; Milton et al., 2016), highlighting three important points. First, the importance of validating constructs from autistic perspectives. Second, the demand for suitable measuring instruments and third, the formulation of support strategies that consider autistic needs. These three points suggest that the issue in not simply whether autistic young people experience loneliness, but whether existing conceptualisations are sensitive enough to how loneliness is experienced and expressed. Adopting traditional approaches to understand autistic young people's experiences of loneliness may not fully capture the complexity of how loneliness can present. Feeling misunderstood, disconnected or separated from the world, will remain unnoticed and consequently uncatered for.

In research, loneliness is frequently associated with "negative and unpleasant emotional feelings" (Ozawa de Silva, 2022, p.11) or with "negative affect and emotional distress" (Quadt et al., 2020, p. 698). It is described as a "devastating feeling" (Ernst & Cacioppo, 1999, p.1), as an "unpleasant experience" (Perlman & Peplau, 1981, p.31) and as

an “emotion that can feel unbearable and may include great suffering” (Garnow et al., 2024, p.1). Besides being characterised by well-known feelings of sadness, sorrow and isolation (Cramer & Barry, 1999; Kwan et al., 2020) as previously seen in academic literature, loneliness was described in this study as an ambivalent experience, one which could be both positive and negative.

The use of creative and flexible methods in this study encouraged participants to express themselves whilst minimising a priori assumptions. This allowed for varied and uncommon understandings of loneliness to be made known and to be explored. Participants described, for example, feeling boredom when lonely. Loneliness was also described as being felt in the body, as a somatic expression (Stickley et al., 2016). Loneliness was sometimes a positive mental state, where an individual is separated from others whilst maintaining an affirming inner focus (Weinstein et al., 2023). “True loneliness” has been described by philosophers and clinical psychologists as an essential condition of human existence (Perlman & Peplau, 1982, p.126). Drawing on these perspectives, the experiences described by participants in this study were conceptualised as ‘positive loneliness’, which autistic young people described as an opportunity for self-improvement, creativity and productivity. It is a mental state, that is both challenging and fulfilling.

This description is conceptually different from solitude, which is defined as choosing to be physically separated from others in a dominant interaction with the self (Weinstein et al., 2023) and does not include suffering or distress (Tillich, 1963). This domain of loneliness was described by the participants in this study as combining the pain of an unmet need to belong with the comfort of solitude. It resembles the solitude-loneliness (SOLO) paradox, whereby autistic people seek solitude as a positive regulatory strategy, but this does not address their need to belong (Muris et al., 2026).

The findings can also be considered in relation to Social Motivation Theory (Chevallier et al., 2012), which proposes that differences in social motivation may influence how social interactions are experienced. This perspective may help to contextualise why spending time alone was not necessarily experienced negatively by autistic young people in this study. However, the findings also caution against interpreting reduced social interaction or a desire for solitude as evidence of loneliness or assuming that these experiences necessarily reflect reduced social motivation. Participants described considerable variation in their desire for social connection, and experiences of being alone could coexist with both a desire for belonging and experiences of meaningful connection. Social Motivation Theory therefore provides one possible framework for understanding the findings, but does not account for the complexity or variability of participants' experiences or the contexts in which these experiences took place.

Alongside these perspectives, philosophical and humanistic accounts have conceptualised loneliness in ways that extend beyond its negative emotional consequences. Moustakas (1961) talked about the pain and despair associated with loneliness and also acknowledged it as a creative and productive force that allows meaningful awareness of the self and engagement with deeper aspects of life. Nietzsche (2009) discussed states of constructive loneliness as being essential for creative originality. For Kierkegaard (1992), loneliness is unavoidable, but when endured, it becomes a pathway for the development of self-understanding and authenticity. These alternative perspectives of loneliness challenge and expand dominant understandings and may help change the stigma around loneliness, as well as how autistic people feel about themselves and about using personal strategies to soothe loneliness.

The concept of positive loneliness should not be interpreted as suggesting that autistic people generally prefer to be alone, that loneliness is inherently beneficial, or that painful

experiences of loneliness should be reframed as positive. Rather, it highlights the importance of distinguishing between being alone, wanting to be alone, and experiencing loneliness.

Research with autistic adults has suggested that greater self-acceptance of autistic differences may be associated with reduced loneliness, with some participants describing this as developing over time (Grace et al., 2025). Similarly, in the present study, some young people who described positive loneliness appeared to use periods of being alone as opportunities to engage with things important to their sense of self. This does not mean that they did not desire or value social relationships, but rather that being alone was not experienced as a negative state. For these young people, even when being alone was not necessarily a choice, aspects of the experience could sometimes be valued or experienced as meaningful. In this sense, positive loneliness is not simply a resigned effort to make the best of solitude. It can be an opportunity for self-connection, reflection, and engagement with inner life, including the parts that feel difficult.

It is acknowledged that the term ‘positive loneliness’ may elicit questions and present conceptual tensions. In particular, the juxtaposition of ‘positive’ and ‘loneliness’ may appear contradictory and could potentially be interpreted as suggesting that loneliness is inherently beneficial, that autistic people prefer to be lonely, or that experiences of unwanted loneliness should be reframed as positive, burdening autistic young people with the responsibility of addressing or owning their loneliness. Translating complex psychological processes and experiences into language can be challenging. The term ‘positive loneliness’ was chosen because it reflected patterns identified in participants’ accounts. However, this does not necessarily mean that the term provides the most appropriate or precise way of conceptualising these experiences. Further research, particularly research that continues to centre autistic people's own perspectives, may help to refine both the conceptualisation and the terminology used to describe these experiences.

Stigmatising views of loneliness are stronger for young people because being social is particularly valued during adolescence and young adulthood (Barreto et al., 2022). Recognising that experiences of positive loneliness may sometimes be meaningful or restorative could be helpful for promoting wellbeing and creating spaces for authenticity, while reducing the shame associated with social loneliness. Personal strategies to meaningful aloneness might include being with pets, in nature, having parallel, fictional, and online connections. Activities might include being immersed in interests such as painting, drawing, planning, model making, playing a musical instrument, listening to music, reading, writing, watching television, sewing, designing clothes, or exercising. Using imagination, daydreaming, and immersion in vivid imagery were also mentioned as validating. When previously examined, without input from autistic views, some of these strategies had mixed evaluations (Lisboa White et al., 2024) with researchers considering them maladaptive (such as; Adamo, 2004; Halsall et al., 2021), and others pointing to their potential for promoting wellbeing (notably Acker et al., 2018; Berns, 2016) .

The results from this study are an invitation to consider these personal ways of promoting connection and soothing loneliness for autistic young people as constructive and benign. These findings should not be interpreted as suggesting that autistic young people generally prefer to be alone or that withdrawal from social relationships is necessarily positive. This is one of two essential suggestions, the second being approaches that reduce unquestioned social demands and environmental stressors that contribute to how autistic young people feel different and misunderstood by their peers (Heasman, 2018; Milton, 2012). Importantly, recognising the potentially constructive role of ‘positive’ loneliness does not negate autistic young people’s desire for meaningful social connection. Instead, the findings suggest that the relationship between loneliness, connection and being alone is more complex than a simple preference for, or avoidance of, social interactions.

Autistic young people in this study who felt social and emotional loneliness, talked about a desire to belong and feeling included by peers, and how this can be accompanied by hesitance due to many previous negative social experiences. Bullying of autistic people is well documented (Horgan et al., 2022; Milton & Sims, 2016; Weiss & Fardella, 2018; Zablotsky et al., 2014). Especially during adolescence, young people develop an increased awareness of difference and of the stigma associated with autism (Humphrey & Lewis, 2008), which can exacerbate the intensity and occurrence of these negative social experiences at this phase of life. For some participants, therefore, the desire for connection existed alongside an understandable caution about pursuing it.

In this study, loneliness was chosen by some young people to avoid repeated experiences of bullying, rejection, or misunderstanding – the lesser of two evils. This self-imposed distance from peers often came accompanied by shame, inadequacy, guilt, and personal responsibility for their predicament. This association between social exclusion and negative self-perception is also reflected in recent research on autistic adolescents' experiences of belonging in mainstream schools (Pearson et al., 2025). Similarly, autistic young people may experience distress through feeling that they do not belong, difficulties with acceptance and understanding, accumulated effects of masking, self-doubt and sensory mismatch between the person and the environment (Lukito et al., 2025). Research has also highlighted how neurodivergent students may feel emotional burden through lack of belonging and understanding, sensory and environmental demands, inflexible school policies and academic pressures (Kakoulidou et al., 2026; Lukito et al., 2025; Pavlopoulou et al., 2025). This literature suggests that experiences of loneliness cannot always be separated from the social and environmental contexts in which autistic young people are expected to participate. In addition, it provides a contextual lens for understanding the experiences described by participants in this study. Rather than viewing social withdrawal solely as an

individual choice or deficit, or as an inherently and singularly 'positive' experience as discussed earlier, it may sometimes represent a response to environments in which autistic young people experience negative systemic experiences to move away from. In turn, repeated experiences of rejection and discrimination can contribute to internalised stigma (Botha & Frost, 2020), leading to more isolation and less quality of life (Turnock et al., 2022), effects of minority stress.

If avoiding social connection can sometimes represent a response to harmful environments and negative social experiences, attention should be given to what interventions are appropriate. Instead of assuming that the level of social interaction is what needs to be corrected, support might be more efficient if it tries to understand what autistic young people want from their relationships and what makes connection possible or difficult for them. Recommendations based on these findings include evaluating when and how to intervene based on autistic young people's desires to have relationships (Calder et al., 2013), working collaboratively and considering autistic young people's needs when planning support interventions (Elmose, 2019; Pellicano & Stears, 2011). Moving away from standardised approaches has been suggested for alleviating loneliness for non-autistic young people (Eccles & Qualter, 2021), and according to the findings in this study, this could be useful for autistic peers too. In practice, this means accepting different ways of feeling lonely or connected and releasing autistic young people from 'typical' expectations related to a predetermined number of social relationships. These findings support previous research that shows that some autistic young people can have a lower, or different drive for social interactions (Sumiya et al., 2018), and that stigma associated with aloneness is sometimes what interferes most with feelings of loneliness. Autistic young people will blossom if they feel accepted and valued (Hamilton & Petty, 2023; Mesa & Hamilton, 2022b). However, individualising support is only part of the required response. If autistic young people's

experiences of loneliness are shaped not only by their individual preferences but also by the social environmental contexts in which they live, reducing loneliness also requires attention to those contexts.

Many of the hindrances to social connection mentioned by our participants are created socially. Shifting the focus from the individual to the behaviour of communities and societies might be the key to better understanding loneliness (Morrison & Smith, 2017) and addressing it. This shift in perspective is not new to other areas of autism research. Differences in sociality, for example, are not located within the individual but seen as "historically and culturally situated in discourse" (Milton, 2012, p. 886). The proposed shift from medicalised views to neurodiversity in autism science is a further example of the effort being made to challenge deficit-based investigations, moving the focus from the individual to their broader contexts (Pellicano & den Houting, 2022; Sonuga-Barke, 2023). Based on these developments in autism research, the findings of this study suggest that loneliness may similarly need to be understood not simply as an individual experience, but as an experience shaped by the social conditions in which autistic young people are expected to socially connect.

This study suggests a similar paradigm shift when investigating loneliness for autistic young people: moving the focus from individual social deficits to the structural barriers that disable connection for autistic young people. To achieve this paradigm shift, those supporting autistic young people can borrow compassion-informed practices from the educational and therapeutical fields that suggest actions such as noticing distress, active listening, curiosity and empathic responses (Hamilton & Petty, 2023). A recent article by McGreevy et al. (2026) aligns with this suggestion and recommends experience-sensitive approaches to "support well-being from an existential, humanistic view, grounded in acceptance of autistic diversity" (p. 107). When understood in this way, loneliness can be conceptualised as shaped partly by

the fit between autistic young people and their social environments, which means that supporting connection will require changes not only in how young people are supported, but also in the environments in which connection takes place.

Social contexts influence how young people engage in identity construction (Ringland et al., 2016) and consequently how they connect with others. Steps that could enable social connection for autistic young people include closing the gap between different styles of communication and social expectations; promoting acceptance and creating space for authenticity, where young people feel acknowledged and valued; providing familiarity, predictability, support, trust, understanding, and warmth; and re-thinking spaces to accommodate sensory needs.

In summary, the findings of this study suggest that autistic loneliness is broader than the absence or closeness of social relationships. The findings offer a revised conceptualisation of loneliness that is multidimensional and includes existential, experiential, and positive loneliness. Existential loneliness arises from feeling fundamentally different from the world; experiential loneliness arises from the perceptions that others cannot understand autistic ways of experiencing the world; and positive loneliness is a challenging but meaningful experience that allows autistic people to engage in alternative forms of connection. These forms of loneliness are shaped by the degree to which autistic young people feel understood, accepted and able to exist.

In practice, these findings suggest that understanding autistic loneliness requires attention to both the experience of the individual and the social conditions in which that experience develops. The contribution of this study is therefore not only the identification of additional dimensions of loneliness, but a broader conceptualisation in which loneliness is understood as relational, contextual and potentially ambivalent.

Such insights have implications for research theory and practice. Research and theory should move beyond measuring and conceptualising loneliness only in terms of social relationships and these findings can offer a starting point from which assessment tools can evolve and conceptualisations can become multidimensional. Practically, these findings can support the development of interventions that better align with autistic needs (Beams et al., 2021) and that recognise positive loneliness and autistic strategies of connection as legitimate.

Strengths and Limitations

This study offered a re-conceptualisation of loneliness that includes the views of autistic young people and may be of interest to members of the autistic community, school staff, clinicians and support workers working with autistic clients, and academics and researchers interested in loneliness. Participatory approaches were used when consulting with autistic people at different stages of the study. Choice was offered in how people wanted to engage both during consultation, data collection, and analysis points. Although efforts were made to be inclusive, the study is limited to perspectives from autistic young people in the United Kingdom who could engage with oral or written communication. It is acknowledged this is not representative of all autistic people. Research conducted by autistic researchers, who determine all stages of study (Botha, 2021) is valued and recognised as fundamental for the advancement of the field of autism research.

Bridging Section

Study Two of this thesis offered an extended conceptualisation of loneliness that includes autistic perspectives and less studied facets of loneliness such as existential, experiential and positive loneliness. The second set of findings explored how social contexts can influence how young people engage in identity construction (Ringland et al., 2016) and consequently how they connect with others.

The study made a conceptual contribution to the field of autism research by offering a new way of understanding loneliness that includes autistic views. This was done by moving away from predominant conceptualisations of loneliness framed by neurotypical experiences. Consistent with the ontological stance of the thesis, the findings also reinforced the need for a shift in perspective (Pellicano & den Houting, 2022; Sonuga-Barke, 2023), moving the focus from individual social deficits to the structural barriers that disable connection for autistic young people.

The next step of this thesis was to apply this new conceptualisation of loneliness in the theoretical development of a scale appropriate for use with autistic young people.

Chapter 5: Developing a Scale of Belonging and Loneliness for Autistic Young People

This chapter describes the theoretical development of a loneliness scale in collaboration with autistic young people and those who support them. The new scale was based on two key findings: (1) an evaluation of existing measures conducted in Study One, a systematic review of the literature about loneliness for autistic young people (Lisboa White et al., 2024), and (2) qualitative descriptions of loneliness from autistic perspectives generated in Study Two, a creative and flexible exploration of the experiences of loneliness for autistic young people. The new scale, named Experiences of Loneliness Scale for Autistic Young People (ELSA), is a 52-item scale distributed into six domains of loneliness (social, emotional, global experiential, existential and positive loneliness). It is intended for use by teachers, parents, psychologists and therapists as a tool for assessing experiences of loneliness for autistic young people.

Introduction

Loneliness is part of human experience, and the effects of prolonged and persistent loneliness can be detrimental to health (Deckers et al., 2017; Holt-Lunstad et al., 2015), mental wellbeing and cognition across the life span (Cacioppo & Hawkley, 2009). When the experiences of autistic young people are the focus of investigation, loneliness is less well understood. Autistic young people have consistently reported experiencing more loneliness than their non-autistic peers (Bauminger et al., 2003; Chang et al., 2019; Feldhaus et al., 2015; Lasgaard et al., 2009; Locke et al., 2010). However, the systematic review conducted as Study One of this thesis showed that measuring instruments that have been used to assess the experiences of loneliness for autistic young people, have been based on ‘typical’ understandings of loneliness and connection that do not include autistic phenomenology (Lisboa White et al., 2024).

The use of standardised measuring instruments that have not been specifically developed for autistic people has been critiqued. Autistic people have raised concerns over the validity and risk of studies that use measuring instruments that have not been tested or adapted for autistic users (Nicolaidis et al., 2019). Some of the concerns mentioned include problems with language complexity, imprecise response options and inability to fully capture the construct being measured. In line with these arguments, Grace et al. (2022) found that researchers investigating experiences of loneliness for autistic adults did not fully examine the validity of measuring instruments and did not employ in-depth involvement of the autistic community when developing new loneliness measures. Similarly, Caruana et al. (2021) commented on the limitations of the Autism Quotient 10 scale (AQ10), stating that its social constructs are based on neurotypical social norms, such as "capacity to understand and interact with others" (p. 1031). Other examples of measures that have not considered autistic perspectives include tools used to assess depression and suicidality for autistic people , discussed in systematic reviews conducted by Cassidy et al. (2018a, 2018b). Offering further critical commentary on the use of standardised wellbeing scales with autistic people, the suitability of measures of anxiety for autistic individuals was discussed by Rodgers et al. (2016). In their analysis of the Revised Children's Anxiety and Depression Scale (RCADS), scales items that assessed social phobia – typically associated with fear of negative evaluations by others – were associated, for autistic young people, with performance-related anxiety, possibly reflecting worries about rule-breaking or making mistakes. This shows how the items on the original scale did not fully represent autistic experiences.

Efforts have been made to evaluate and adapt current measures of loneliness for autistic adults. Notably, the UCLA Loneliness Scale and SELSA had their suitability examined by a group of autistic adults and results highlighted, for example, that the items based on neurotypical norms of sociality did not reflect the nuances of autistic experiences of

loneliness (Grace et al., 2024). Participants in this study mentioned that the UCLA Loneliness scale assume that the desire or pleasure of being sociable is universal, excluding other forms of feeling connected. Equally, participants pointed out that the scale items from SELSA focus on relationships as something desired by all respondents and assume that the absence of friendships or romantic relationships lead to feelings of loneliness. More recently, the UCLA Loneliness Scale was adapted in collaboration with autistic individuals (Love et al., 2025). The adaptation involved the refinement of 10 items from the original 20-item scale and the removal of three items, resulting in a 17-item scale. After psychometric analyses, the scale was reduced to 15 items. This unidimensional assessment of loneliness offers a total score of self-reported loneliness, where higher scores indicate higher loneliness.

The Investigation of Loneliness for Autistic Young People

The systematic review conducted in Study One highlighted that for autistic young people, five measuring instruments have been consistently used to investigate loneliness in research literature (Lisboa White et al., 2024): the Loneliness Rating Scale (Asher et al., 1984), the UCLA Loneliness Scale (Russell, 1996), Loneliness and Aloneness Scale for children and adolescents (LACA, Marcoen et al., 1987), the De Jong-Gierveld Loneliness Scale (De Jong-Gierveld & Kamphuis, 1985) and the Peer Network and Dyadic Loneliness Scale (PNDLS, Hoza et al., 2000). These measuring scales have been widely evaluated and recognised as having excellent psychometric properties for different groups of people. For example, the LACA has shown to have strong validity and reliability across diverse cultural contexts (Goossens & Maes, 2017). The de Jong-Gierveld Loneliness Scale has shown validity and reliability across seven countries of the United Nations (De Jong Gierveld & Van Tilburg, 2010). However, they have not been specifically designed or validated for autistic young people. When evaluating the suitability of standardised measures, consideration should be given to how the domain that is being measured has been identified (Boateng et al., 2018).

In this case, the concept of loneliness has been limited to social and emotional domains and has been based on 'typical' perceptions and experiences of the number and quality of friendships and social relationships only, possibly misrepresenting autistic experiences of loneliness.

Scale items that refer to the quality or number of social relationships are useful to assess social and emotional loneliness. Despite the prevalence of these domains in loneliness research, connection and loneliness have been described by autistic young people as extending beyond these domains, reflecting more nuanced views. In Chapter Four, it was reported that when described by autistic young people, loneliness included feelings of being invalidated and excluded despite having other people around them. This was identified as existential loneliness. They also described feeling lonely when they felt that their experiences were not shared or understood by others. This was identified as experiential loneliness. Perhaps, more surprisingly, when contrasted with existing conceptualisations (Perlman & Peplau, 1981; Weiss, 1973), loneliness is described as an ambivalent feeling, a mental state that although challenging, can be fulfilling by offering opportunities for self-improvement, creativity and productivity. This was identified as positive loneliness.

Understanding Connection for Autistic Young People

If standardised measuring instruments were based on conceptualisations of loneliness that came from 'typical' perspectives only, the same is true for the concept of connection. Another limitation of standardised loneliness measures used for investigating the experiences of loneliness for autistic young people is that the understanding of connection is mostly limited to a description of people's relationships (i.e., friendships) (Lisboa White et al., 2024). In the qualitative investigation presented in Chapter Four, autistic young people discussed feeling connected in alternative ways. They described feeling 'not lonely' when interacting with pets, or when in nature, when taking part in activities as an observer, when

enjoying quiet companionship and when having online and fictional connections. Activities that promoted feeling connected included being immersed in personal interests (such as reading, drawing or playing a musical instrument) and immersion in imaginary worlds. Previous research supports these findings. Turning within, using imagination and fictional companions (Causton-Theoharis et al., 2009; Davis et al., 2018) and anthropomorphising (Caruana et al., 2021) have been reported as personal and meaningful strategies that differ from traditional representations of social connection.

Personal strategies that promote feelings of connection for autistic young people can be considered authentic and soothing, however, within a neurotypical framework of investigation, they can be judged to be maladaptive or inadequate (Adamo, 2004; Halsall et al., 2021). The issue with approaches that do not recognise personal strategies as meaningful, is that they predetermine what it means to be lonely or not lonely and consequently, promote interventions that focus primarily on improving social skills and increasing opportunities for social connection.

There is evidence that social skills training can reduce feelings of loneliness and can foster feelings of belonging (Gantman et al., 2012). For individuals who want to have more social relationships, social skills training coupled with an increase in social opportunities can be used as a strategy to promote connection (Masi et al., 2011). However, for individuals who express less desire for social interactions (Sumiya et al., 2018), or increased anxiety and fatigue associated with masking/camouflaging (Chapman, 2020), these strategies might feel like trying to conform to neurotypical social demands, which can lead to increased loneliness (Grace et al., 2022). Interventions that support social connection are not inherently problematic, but performing connection is not equivalent to feeling meaningful connection. In other words, there is a need for a more nuanced understanding of what constitutes

meaningful connection. That should include the development of valid constructs and the use of aligned assessment tools that allow for a multitude of ways of being.

A Loneliness Scale Suitable for Autistic Young People

Measuring scales in the field of social sciences are developed to capture human experiences, such as feelings, behaviours or actions, which cannot be harnessed in a single variable (Boateng et al., 2018). By having suitable measures to assess subjective constructs, mental states can be identified, and early, suitable interventions can be targeted, contributing for the promotion of quality of life (Streiner et al., 2015). Quality criteria for measuring subjective constructs have been historically based on measures of reliability and validity (Elasy & Gaddy, 1998). These refer to the degree to which a measuring tool produces repeatable results under the same conditions and the extent to which a method measures what it is intended to measure (Ishtiaq & Ishtiaq, 2021). However, cultural and contextual appropriateness have more recently become important markers for determining quality of measuring scales (Almanasreh et al., 2019). These mean how well a scale aligns with the cultural and real-life contexts of the groups it is used with, in addition to its validity and reliability.

In research, the choice and suitability of measuring instruments determine what and how a construct is measured. These decisions can shape the research process, the data that is generated, how findings are interpreted and the credibility of results (Repke et al., 2024; Slater & Hasson, 2024). Based on this argument, it can be said that instruments that are poorly aligned with the experiences of the group being investigated or the construct of interest, risk generating data that are methodologically sound yet meaningless. In the field of loneliness for autistic people this means that standardised measures of loneliness might align with some subjective autistic experiences and measure these consistently. However, they can fail to reflect nuances in experiences of rejection, misunderstanding and positive loneliness,

generating misleading results (Grace et al., 2024). In addition, such outcomes will likely promote inadequate interventions, as previously discussed.

To develop a loneliness scale that feels relevant and suitable for scale respondents, it is recommended to involve people with lived experience. Grace et al. (2022) endorsed extensive consultation from and collaboration with the autistic community in the adaptation or development of measuring instruments, like the work done by McConachie et al. (2018) in the field of quality of life. Developing a measuring instrument with extensive contributions from future scale users can facilitate important insights about personal experiences to individuals and the people who support them (Grace et al., 2022; Streiner et al., 2015).

Beyond methodological considerations of validity and reliability, developing measures in collaboration with autistic people is a step towards promoting epistemological justice. Investigating loneliness without the inclusion of autistic perspectives, reinforces the dominance of a 'typical' way of experiencing connection and wellbeing, and the need to 'fix' autistic people to fit a 'normality' mould (Fletcher-Watson et al., 2019; Milton, 2017). Pathologising paradigms can only be challenged when autistic people are acknowledged as epistemic agents (Chapman & Carel, 2022) and are included in the research cycle.

The purpose of this study was to theoretically develop a loneliness scale that included a critical review of existing measuring instruments and autistic subjective experiences of loneliness and connection, in collaboration with autistic young people and those who support them. The first and second studies of this thesis offered a foundation for the theoretical development of the scale. In line with recommendations to identify and evaluate existing measures (Morgado et al., 2018; Streiner et al., 2015) the systematic review offered a review and critique of existing loneliness scales used to investigate loneliness for autistic young people. Study Two in turn, contributed to the conceptual integrity of a scale by offering an

extended understanding of the construct of loneliness from autistic perspectives. The research questions that guided the current study were a) what scale items represent loneliness for autistic young people?; b) are the proposed scale items clear and easy to understand?; and c) is the scale appropriate for autistic young respondents?

Practical implications of a new loneliness scale specifically designed for autistic young people include improving the identification of loneliness, facilitating access to appropriate support, and recognising autistic-led strategies as meaningful ways of coping with loneliness.

Funding

The present study was funded by a graduate grant offered by the Organization for Autism Research (OAR Grant Number: 2024G02). This funding covered travel expenses for the main researcher, participant compensation, refreshments during participant sessions and the commissioning of an artist to produce illustrations representing the different domains of loneliness. These illustrations were used to produce a research report for the dissemination of findings of Study Two.

Community Involvement

Meaningful outcomes of research are those that have an impact on individuals' everyday life, helping to maximise potential and quality of life (Miller & Daly, 2013). Measuring subjective experiences and designing interventions from neurotypical perspectives risks imposing assumptions about what might be at stake for autistic individuals. Despite good intentions, this at times, means overlooking autistic experiences and needs (Elmose, 2019). The topic of investigation for the thesis, experiences of loneliness for autistic young people, had its relevance validated by members of the autistic community (Lisboa White et al., 2024). This was done through a PPI group detailed in Chapter Three.

During Study Two, detailed in Chapter Four, the aim was to place autistic perceptions at the foreground of the exploratory investigation by a) having autistic input in the study design; b) offering participants options in how they wanted to engage with data collection through creative and flexible methods of participation; and c) inviting autistic young people to take part in data analysis. For the current study, young people and those who support them collaborated with a) the evaluation of content validity of candidate scale items; b) pre-testing of the scale; c) formatting of the survey; and d) evaluation of response range and options.

As with the other instances of autistic contribution in this thesis, consideration was given to creating inclusive environments (Gatfield et al., 2018). During every phase of collaboration flexible methods of participation were employed and participants were asked whether any accommodation of needs was necessary. The objective of these practices was to promote engagement and reduce challenges to increase representativeness.

Methods

The methods used for the theoretical development of the ELSA were based on literature for best practices in scale design (Boateng et al., 2018; DeVellis, 2017; Morgado et al., 2017; Streiner et al., 2015) and successful examples of scale development in areas of health and psychology (Bearss et al., 2016; Fok & Tsang, 2005; Rodgers et al., 2016; Thomas, 2011; Williams & Kristjanson, 2009). The development of the scale was an iterative process of constant revisiting and refining of candidate items, guided by evaluations of existing literature and specific feedback from academics, clinicians and people with lived experience, which informed the revision, exclusion or re-wording of items.

The process of scale development was divided into four distinct phases (Boateng et al., 2018; DeVellis, 2017). Phase one focused on item generation. Phase two included the assessment of content validity by a panel of experts. Phase three included the assessment of

content validity by focus groups consisting of autistic people and the communities who support them. Phase four entailed the pre-testing of the scale by autistic young people. The sections below were structured to address first the methods used, followed by the results of each phase in detail. The flowchart (Figure 19) illustrates the process.

The study received ethical approval from the School of Education, Language and Psychology Research Ethics Committee at York St John University (ETH2324-0251).

Phase 1: Item Generation

The generation of candidate items for the new scale of loneliness for autistic young people included a combination of deductive and inductive methods (Boateng et al., 2018), both detailed in this section. The first step (deductive approach) helped to define the construct of loneliness, whilst the latter (inductive approach) moved it from the abstract realm to its manifest forms, which means capturing the construct in real-world terms as something concrete that can be measured or observed.

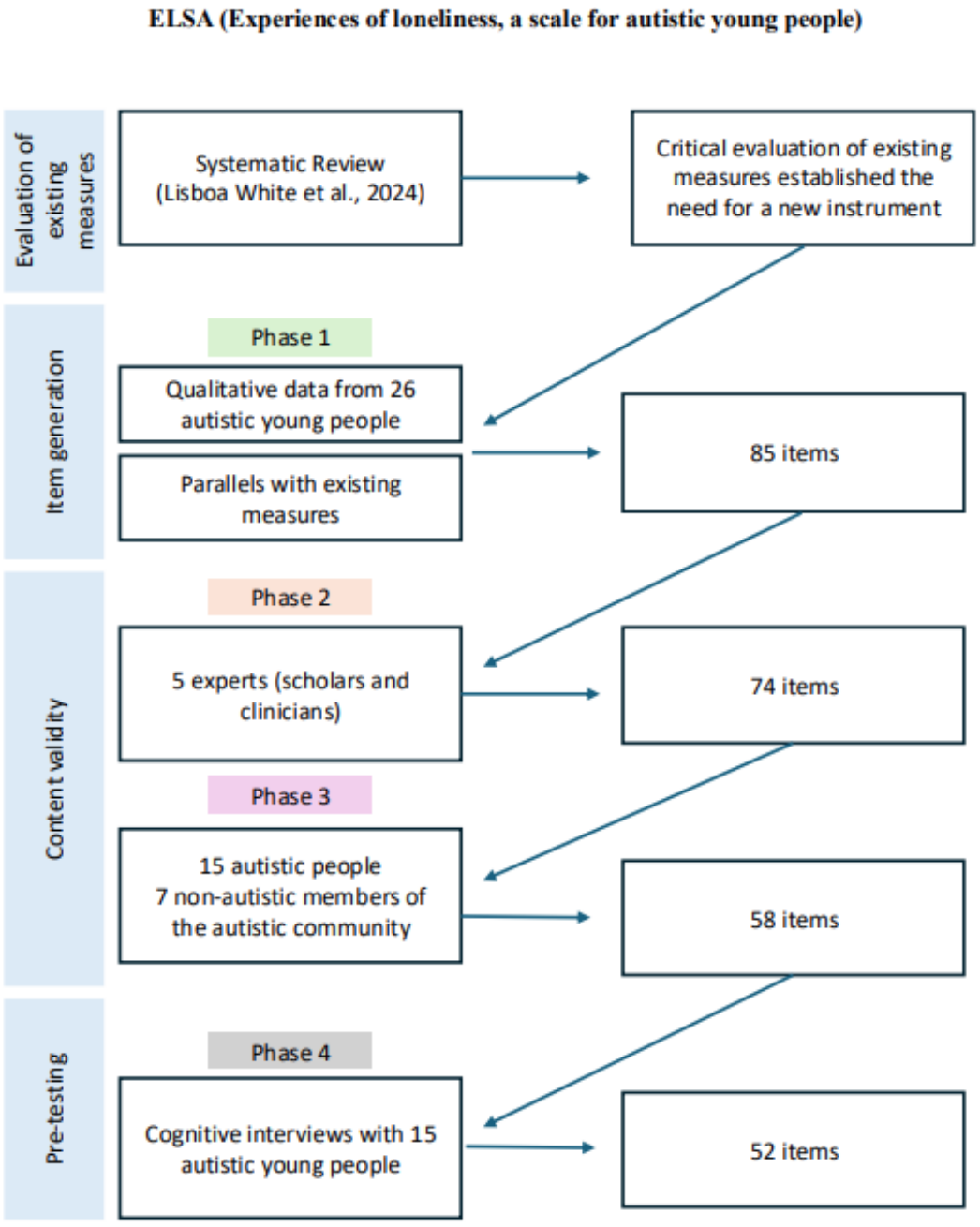
The deductive methods used to generate candidate items included a) assessing literature about loneliness, its conceptualisations and perceptions (e.g., Cramer & Barry, 1999; Goosens et al., 2009; Heinrich & Gullone, 2006); and b) assessing existing scales for useful items and terms that described feelings and emotions associated with loneliness. The inductive methods used on the process of item generation included a) creating items from the qualitative descriptions of loneliness (Streiner et al. 2015) collected during study two of the thesis and b) drawing parallels from existing measures of loneliness, with the objective of improving created items or borrowing existing items.

The first step in creating candidate items was to define the domains of loneliness. Social, emotional, existential, experiential and positive loneliness were the five domains identified in Study Two. Global loneliness was identified and added later during the

examination of existing scales as it appeared in several established measuring instruments (Asher et al., 1984; Bauminger et al., 2003; De Jong Gierveld & Kamphuis, 1985; De Jong Gierveld & van Tilberg, T., 2010; Hoza et al., 2000; McKenna-Plumley et al., 2023; Russell et al., 1980).

Figure 19

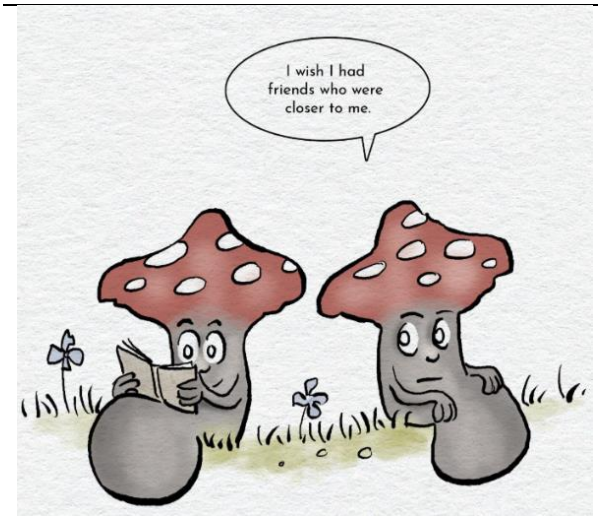
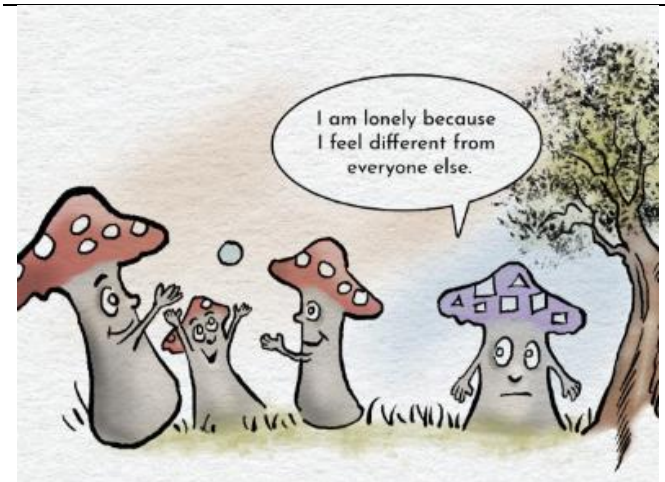
Flowchart Illustrating the Development of the ELSA

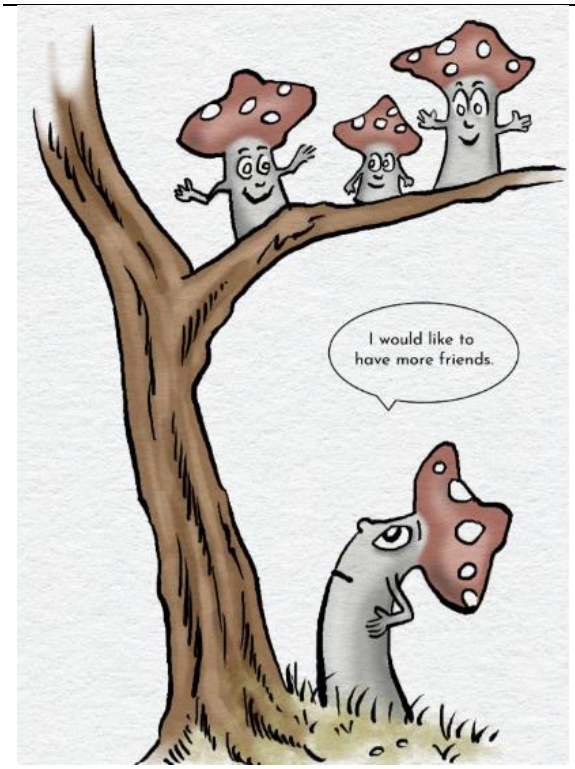


The six domains of loneliness were defined by referring to autistic young people's descriptions and information found in literature (e.g., Bolmsjö et al., 2019; Cacioppo et al., 2015; Hawkley & Cacioppo, 2010; Larsson et al., 2017; Maes et al., 2022; McKenna-Plumley et al., 2023; Moustakas, 1961). Table 14 shows the definitions alongside illustrations commissioned specifically to support the dissemination of findings. The illustrations were funded by the OAR graduate grant and created by illustrator Matt Cole. Characters were based on previous work done by the supervisory team in collaboration with autistic people.

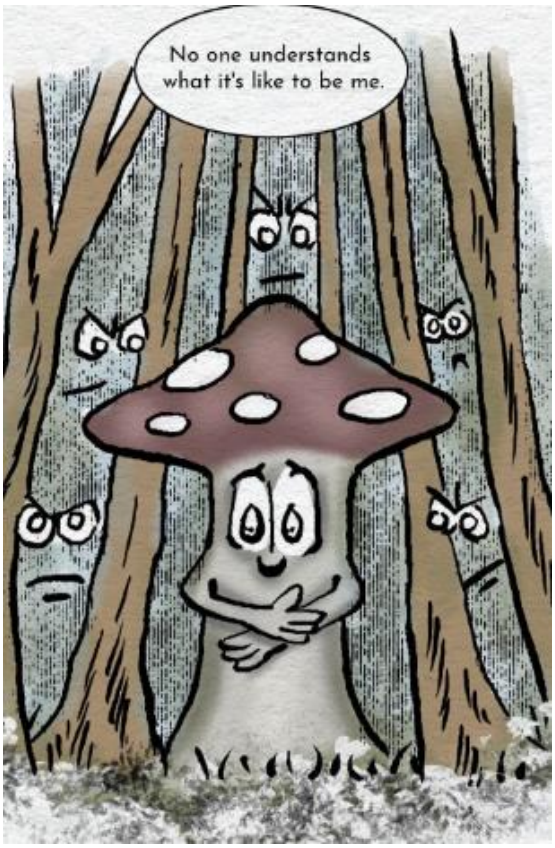
Table 14

*Definitions of the Six Domains of Loneliness According to Autistic Young People**

Illustration	Definition
	**Emotional loneliness** is when you miss having close relationships.
	**Existential loneliness** is when you feel you are different from everyone else. You feel like an outlier, odd or irregular, as if you are not part of this world.



Social loneliness is when you feel you do not have enough friends.



Experiential loneliness is when you feel that no one understands the way you experience the world. No one understands what it is like to be you in the world.



Positive loneliness is when you feel that in the absence of others you can focus on things that are important for you and that make you feel fulfilled. It can be a challenging feeling, but it is meaningful and wanted.



Global loneliness is a general feeling of loneliness that might include several of these domains. It is just a feeling that makes you feel down or flat.

*Illustrations by Matt Cole

Next, candidate items were crafted from the extracts of lived experience collected during Study Two (Table 15). Incorporating first-hand knowledge to item generation is a recommended step in scale development (Sreiner et al., 2015). This was particularly important for this scale, as one of its aims was to address worries about inadequacy of measures and to add subjective elements that were relevant to autistic young people's experiences (Grace et al., 2022; Nicolaidis et al., 2019).

Table 15

Examples of How Extracts of Lived Experience Were Used to Create Candidate Items

Extracted of lived experience	Candidate item
Qamri: I used to have a boyfriend, but when we broke up then I did feel lonely. But then, but then, I managed to speak to my family about it.	I have people I can talk about things that bother me.
Adam: Being in a community and talking to other people about something you like can help bring connections.	I have people with similar interests to mine.
Max: I use my imagination a lot. LLW: When you're using your imagination, do you feel lonely ever? Max: Not really, no.	I enjoy using my imagination.
Emily: Um, (.) because I felt like there wasn't really anyone like me.	I feel different from other people my age.
Richard: I got much different thoughts like I'm always thinking different and feeling different.	

As the items were created, they were organised into conceptual categories that represented feelings associated with each of the six domains (Global, Social, Emotional, Existential, Experiential and Positive Loneliness). For example, the domain of Social Loneliness had two conceptual categories based on autistic young people's satisfaction with their number of relationships and their perception on the adequacy of their social skills, which were named as 'Perceived Social Network (Number of Relations)' and 'Perceived Social Adequacy'. These two conceptual categories ended up with seven and ten candidate items respectively.

The next step was to check existing measuring instruments for any parallels between new and existing items (Table 16). This enabled a revision of the created items and the domains being measured. The comparative analysis was guided by questions like: How are existing and new items similar/ different? How does this item add to this domain in relation to autistic experiences? How does this item fail/succeed to represent autistic experiences as described in Study Two?

The instruments chosen to support the development of candidate items were scales that have been previously used for investigating loneliness for autistic young people as identified by Study One (Lisboa White et al., 2024). In addition, scales that measure domains that were relevant for this study, such as existential loneliness, were also used. The chosen measuring instruments included the Children's Loneliness and Social Dissatisfaction Scale (Asher et al., 1984), the modified Asher scale used by Bauminger et al. (2003), the Brief Scale of Existential Loneliness (BSEL) (McKenna-Plumley et al., 2024), The De Jong Gierveld short scale for emotional and social loneliness (De Jong Gierveld et al., 2010), the original De Jong Gierveld scale (De Jong Gierveld et al., 1985), the Peer Network and Dyadic Loneliness Scale (PNDL) (Hoza et al., 2000) and the revised UCLA Loneliness Scale (Russell et al., 1980).

Parallels between candidate items and existing instruments were used to improve the quality of each item. A good quality item is easy to read and to understand; it should be as concise as possible, ask only one question at a time, and avoid jargon, value-laden words, and ambiguities (Streiner et al., 2015). New items created to assess global, social and emotional loneliness were the ones with the largest number of similar items within existing measuring instruments. For example, the item "I feel lonely" appeared twice in the Children's Loneliness Scale as "I'm lonely" and "I feel lonely", once in the UCLA Loneliness Scale as a reversed score item "I do not feel alone", and once on the BSEL as "I feel like I am

ultimately alone in life". When very similar, new items were changed to mirror the wording of existing measures. Adopting previously used items when creating a new measuring instrument is common practice in scale development (Streiner et al., 2015). There is no need to create new items when the existing ones have been repeatedly tested and shown to be psychometrically sound.

Existential, experiential, and positive domains of loneliness had fewer parallels with existing loneliness scales. Some of the items within the domain of existential loneliness appeared in the BSEL scale. For example, the item "I feel completely alone in the world" appeared as "I feel utterly alone in the world". Items that described positive autistic experiences of loneliness were not recognised in current measures. An example is the item "I have pets who are like friends". This item was created from narratives that described deep personal connections with pets as being satisfactory and as contributing to feelings of not being lonely.

A pool of 85 candidate items was generated from qualitative data and from parallels made with existing measures. According to DeVellis (2017), having an initially large pool of items increases the chances of adequately representing the construct, thus ensuring content validity. At later stages, the scale can be reduced, as items are evaluated and refined (Steiner et al., 2015), in this case by scholars, clinicians, autistic people and those who support them.

Table 16

Candidate Items and Parallels with Existing Measuring Instruments

Dimension	Conceptual category	No	Items	Parallels with existing scales	
				Scale	Original item
Global loneliness	General feeling of loneliness	1	I feel lonely.	Asher et al.	I'm lonely.
				Asher et al.	I feel alone.
				UCLA	I do not feel alone.
				BSEL	I feel like I am ultimately alone in life.
		2	I often feel bored.	Bauminger et al. (social)	I feel bored during most of the free time in school.
				De Jong Gierveld (short/original)	I experience a general sense of emptiness.
				PNDL	Some kids are often bored when they're with other kids.
		3	I feel empty.	De Jong Gierveld (Short/Original)	I experience a general sense of emptiness.
		4	I feel low.	Bauminger et al. (emotional)	I feel very sad in class.
Social loneliness	Perceived social network (number of relations)	1	I have people I like to be around.	UCLA	I feel in tune with the people around me.
		2	I have got lots of people in my life.	Asher et al.	I don't have any friends.
				Asher et al.	I have lots of friends.

				UCLA	I lack companionships.
		3	I have people I feel comfortable with.	UCLA	I feel in tune with the people around me.
		4	I wish I had more friends.	De Jong Gierveld (short/original)	I miss having people around.
		5	I have people with whom I can share day-to-day-activities.	UCLA	I can find companionships when I want it.
				Asher et al.	I have nobody to talk to.
				De Jong Gierveld (original)	I miss the pleasure of the company of others.
				PNDL	Some kids usually have other kids to do things with.
		6	I have people I can talk to and have a good time with.	UCLA	I can find companionships when I want it.
				Asher et al.	I don't have anyone to play with.
				PNDL	Some kids don't have anyone special their age to share things with.
		7	I would like to have more people to talk to everyday.		
	Perceived social adequacy	8	I find it difficult to connect with people at school/college.	Asher et al.	It's hard for me to make friends.
				Asher et al.	I don't get along with other children.
		9	I find it difficult to connect with people out of school/college.	Asher et al.	It's hard for me to make friends.
		10	I know how to start conversations when I am in a group of people.	Asher et al.	I'm good at working with other children.
		11	I know how to maintain conversations when I am in a group of people.		
		12	I find it difficult to show other people I want to connect with them.		
		13	I find it difficult to be social.	Asher et al.	It's easy for me to make new friends at school.
				Asher et al.	I don't get along with other children.

		14	I can make new friends.	Asher et al.	It's hard for me to make friends.
		15	I find it easy to deal with people.	BSEL	I struggle with the feeling that I cannot connect fully with others.
				Asher et al.	It is easy for me to make new friends at school.
				Asher et al.	It's hard for me to make friends.
				UCLA	I am an outgoing person.
				UCLA	I am unhappy being so withdrawn.
		16	Relationships are straight-forward and simple.		
		17	I feel like withdrawing from social activities.	UCLA	I am unhappy being so withdrawn.
Emotional loneliness	Perceived close relationships	1	I have people I can talk to about things that bother me.	Asher et al.	It is easy for me to make new friends at school.
		2	I have people who I feel close to.	Asher et al.	It's hard for me to make friends.
				UCLA	I am an outgoing person.
				UCLA	I am unhappy being so withdrawn.
				UCLA	There are people I feel close to.
				PNDL	Some kids have someone their age who is a really close friend.
		3	I feel content with myself and other people.	De Jong Gierveld (original)	I find my circle of friends and acquaintances too limited.
		4	I feel I have people who are there for me if I need anything.	Asher et al.	I can find a friend when I need one.
				Asher et al.	There is nobody I can go to when I need help.
				De Jong Gierveld (short/original)	There are plenty of people that I can lean on in case of trouble.
				UCLA	I can call on my friends whenever I need them.
				De Jong Gierveld (original)	There is no one I can turn to.
				UCLA	There are people I can turn to.
				PNDL	Some kids have a friend that is always there for them when they need it.
		5	I have people who care about me.	De Jong Gierveld (short)	There are many people that I can count on completely.

				PNDL	Some kids wish they had a friend that really cared about how they fell inside.
				PNDL	Some kids have a friend that they know will always care about them.
		6	I have people who are interested in my wellbeing.		
		7	I rely on my family for close relationships.		
		8	I have people who want to listen to me.	De Jong Gierveld (original)	There is always someone I can talk to about my day-to-day problems.
				UCLA	There are people I can talk to.
		9	I have people with whom I have deep connections with.	UCLA	My social relationships are superficial.
		10	I have people who can give me emotional support.		
		11	I am well-liked by people in my school / college.	Asher et al.	It is hard to get other kids to like me.
				Asher et al.	I am well-liked by the kids in my class.
				PNDL	Some kids feel like most kids like them.
		12	I am well-liked by people who are important to me.		
Existential loneliness	Feelings of acceptance / rejection	1	I feel I am included at my school / college.	PNDL	Some kids feel lonely a lot because they wish other kids included them more.
				Asher et al.	I feel left out of things.
				UCLA	I feel part of a group of friends.
				UCLA	I feel left out of things.
				PNDL	Some kids really feel like they're part of a group.
		2	I feel I am accepted as I am.	PNDL	Some kids hardly ever feel accepted by others their age.
		3	I feel rejected.	De Jong Gierveld (short/original)	Often, I feel rejected.
				UCLA	I feel isolated from others.
				PNDL	Some kids almost always feel left out when they're with others their age.
	Feelings of separation / belonging	4	I feel different from other people my age.	BSEL	I struggle with the feeling that I am separate from other people.
				BSEL	I feel an upsetting distance between myself and other people.

		5	I feel there are other people like me.	UCLA	I have a lot in common with the people around me.
		6	I fit in.	PNDL	Some kids feel like they really fit in with other kids.
		7	I feel completely alone in the world.	BSEL	I feel utterly alone in the world.
		8	I am wanted around at school / college.		
		9	I have enough people who make me feel good about myself.		
		10	I feel misunderstood.		
		11	I feel judged by others.		
	Perceived space for authenticity	12	I can be myself around people.		
		13	I hide my true self most of the time.		
		14	I have people with similar interests to mine.	UCLA	My interests and ideas are not shared by those around me.
		15	I feel connected to someone when we have the same interests.		
		16	I have people who "get me."	Bauminger et al. (emotional)	I don't have any friend in class who really know me.
				UCLA	No one really knows me well.
				UCLA	There are people who really understand me.
		17	I have places where I can be myself.		
Experiential loneliness	The influence of unique experiences	1	My anxiety makes it difficult for me to be social.		
		2	I have people who understand how I experience the world.		
		3	I have people who understand what it is like to be me.		
		4	I have people who understand my autistic needs.		
		5	My past negative experiences with people get in the way of new connections.		
		6	Busy environments can make connections difficult.		
		7	I wish I had more adult support to make friends.		
		8	I feel I can communicate well with people.		
Positive aloneness	Alternative ways to connect	1	I connect with people online and that is enough for me.		
		2	I have personal interests that fulfil my need for people.		
		3	I have pets that are like friends.		

		4	I don't need people when I am with my pets.		
		5	I enjoy talking to imaginary people.		
		6	I enjoy using my imagination.		
		7	I can connect to fictional characters (in movies, books, series, etc.)		
		8	I can connect meaningfully / best with people over WhatsApp or text messages.		
		9	I enjoy online connections.		
		10	When my senses are stimulated, I do not need other people.		
		11	I enjoy being physically active on my own.		
		12	I enjoy being mentally engaged on my own.		
		13	I enjoy sharing spontaneous conversations with strangers.		
		14	Positive everyday exchanges make me feel I belong.		
		15	I have important objects that help when I feel lonely.		
		16	I like talking to objects.		
	Individual social needs	17	Sometimes, I like being with others.		
		18	Sometimes, I like being on my own.		
		19	I don't feel the need to be around people that often.		
		20	I enjoy time alone.		
		21	I enjoy doing solo activities.		
		22	I prefer in-person connections.		
		23	I wish I had more in-person connections.		
		24	I like being on my own in safe spaces.		
		25	I like feeling lonely.		
	Parallel connections	26	I enjoy watching or listening to people doing things.		
		27	Being around people is enough for me not to feel lonely.	UCLA	People are around me but not with me.

Phase 2: Content Validity Assessed by Independent Experts

Content validity is the adequacy with which an instrument measures a specific construct (Boateng et al., 2018) and is usually assessed by independent experts on the domain of interest or by members of the target population (Boateng et al., 2018; Roebianto et al., 2023). Rubio et al. (2003) highlighted the importance of including the views of people for whom the scale is being developed, as they can judge the level of representativeness of each item and can address issues with language and unclear terms. As the aim of this study was to develop a scale to capture loneliness as experienced by autistic young people, content validity was assessed using feedback from researchers, clinicians, autistic people and their communities. Combining these viewpoints, enabled the construct to reflect both theoretical and lived experience perspectives, strengthening relevance and representativeness of scale items.

The assessment of content validity focused on evaluating each item's relevance and clarity (Roebianto et al., 2023). Relevance was evaluated by examining the extent to which each item reflected the construct of loneliness as defined by the six domains (global, social, emotional, experiential, existential and positive). Clarity was evaluated by identifying ambiguities, double-barrelled questions and language that were difficult to understand.

Participants

Content validity was assessed in two stages. First, a panel of five professionals (3 scholars and two clinicians) reviewed the 85 candidate items. This was followed by focus groups involving participants with lived experience. The professional review was conducted first because panel members were more familiar with scale development and item evaluation, and because reviewing the full set of candidate items was considered an excessive burden for young people. Details about recruitment for the panel and focus groups are described below.

Historically, there has been no standardised guidelines for the ideal number of experts used to judge a new measuring instrument, and many times this has been decided arbitrarily or based on the availability of professionals (Haynes et al., 1995; Lynn, 1986; Polit et al., 2007; Zamanzadeh et al., 2015). Panels with small numbers of experts have sometimes been justified by difficulty recruiting experts (Lynn, 1986). However, there is some agreement amongst scale developers that a new instrument should be evaluated by a minimum of five experts who are knowledgeable about the domain being investigated or are involved in scale development (Boateng et al., 2018; Lynn, 1986; Zamanzadeh et al., 2015). This number can reduce the possibility of chance agreement (Lynn, 1986), albeit not eliminate it completely (Polit et al., 2007).

For this study, 23 professionals were identified as being reputable experts. Their public profiles were related to autism research, loneliness research, clinical work with autistic clients or educational professionals who worked with autistic young people. Criteria for the selection was based on number of publications and/or work experience (Rubio et al., 2003) in the field of autism, loneliness and scale development. Experts were approached via email and were asked to contribute to the development of a new loneliness scale for autistic young people by evaluating the relevance and clarity of candidate items. From these initial contacts, five people expressed interest in taking part and recommended three other participants, who also agreed to evaluate the candidate items. The evaluation panel started with eight experts, however only five returned their complete evaluations (Table 17). This outcome was expected to be representative of those professionals who were more enthusiastic about the new measure of loneliness and more motivated to contribute to this field of research.

Table 17

Panel of Experts who Evaluated the Relevance and Clarity of Candidate Items for the ELSA

	Professional profile
Expert 1	Senior clinical psychologist working with autistic clients
Expert 2	Clinical psychologist working with autistic clients
Expert 3	Research fellow in loneliness and development of loneliness measures
Expert 4	Assistant professor in autism research
Expert 5	Lecturer and researcher with interest in neurodivergent and disabled learners

In line with the inclusive ethos of the thesis, experts who agreed to contribute their views were asked whether they preferred to work online or with a hard copy of the survey. All opted to work online and were sent a personal link to Qualtrics. By accessing the survey, they were presented with more information about their participation, a consent form, and an explanation of how each item should be scored. Then they were asked whether they preferred to register their views using a slider or a multiple-choice format.

Data Collection

There were three criteria for evaluating each candidate item: a) relevance of the content; b) clarity of the item and c) identification of the domain of loneliness (factor). Following examples of previous evaluations of content validity (Roebianto et al., 2023; Rubio et al., 2003), experts were asked to rate the relevance of each candidate item from not relevant to relevant in a scale of 1 to 4 (1=Not Relevant; 2 = Relevant but needs major revision; 3 = Relevant but needs minor revision; and 4 = Relevant). Clarity was similarly scored from not clear to clear (1 = Not clear; 2 = Clear but needs major revision; 3 = Clear but needs minor revision; and 4 = Clear). After each rating, there were spaces provided for

additional comments and experts were encouraged to write any feedback they deemed necessary and helpful to refine items.

At this stage of scale development, it is not common to explore factorial validity, or in other words, how items load on their domains or categories (Hair et al., 2010). However, it was considered useful to check the level of agreement on the categorisation of items, particularly to identify whether any items should be reassigned to a different domain. To identify the factor, experts were presented with a multiple-choice question asking them to choose which domain fit each item best (Global, Social, Emotional, Existential, Experiential, Positive and Other). Domains were accompanied by a definition (Appendix E) and there was space provided for adding comments or identifying other domains of loneliness that were not listed.

The survey also included a question about what type of response would be best suited to the scale. Options included a 5-point Likert scale, a 5-point icon scale (smiley faces accompanied by thumbs up or down), colouring in a bar or moving a slider on electronic versions. Space was provided for any comments.

Analysis

To analyse the results from the panel of experts, scale content validity index (S-CVI), item content validity index (I-CVI), and factor validity index were used (FVI). S-CVI is an index that expresses the proportion of items that were judged content valid overall and the I-CVI expresses the proportion of agreement amongst raters at item level (Zamanzadeh et al., 2015). The S-CVI and I-CVI were calculated based on the scores offered by the panel of experts in relation to the relevance of the items (Zamanzadeh et al., 2015). The FVI was based on how accurate panellists' associations of each item with their respective factors were (Rubio et al., 2003).

There are two methods for calculating S-CVI. The S-CVI/UA requires universal agreement amongst raters whilst the S-CVI/Ave uses the average of I-CVIs (Zamanzadeh et al., 2015). For this study, S-CVI/Ave was chosen for two reasons. First, due to the small number of judges in the panel (N=5). Second, to have a reliable and stable index of content validity whilst not being limited by the rigidity of the universal agreement prescribed by the S-CVI/UA (Polit & Beck, 2017).

The I-CVI was first calculated for each item by counting the number of panellists who rated the item as 'item needs minor revisions' or 'item is relevant' and dividing that number by the number of evaluations (Rubio et al., 2003). To supplement these results and due to the size of the panel (Ayre & Scally, 2014), modified kappa (k) was calculated to account for any agreements by chance (Yusoff, 2019). This extra step made decisions to eliminate or retain an item more robust and evidence-based (Polit et al., 2007). Although items with a k value between 0.60 and 0.74 indicate good agreement (Polit & Beck, 2017), for this study these values were slightly raised to 0.60 and 0.79 increasing opportunities for item refinement (Table 18). Items that fell into this category were reviewed before being retained. This allowed for suggestions to be incorporated and some items to be reworded. See Table 21 in the Results section for results and interpretations.

Despite the lack of guidance on how to analyse the scores on item clarity, the same approach used for relevance ratings was applied. An item clarity validity index (I-ClaVI) was calculated by adding the number of panellists who rated an item 'clear but needs minor revisions' or 'the item is clear', divided by the number of evaluations. Once again modified Kappa (k) was calculated to account for any agreements by chance (Yusoff, 2019). The same parameters used for I-CVI were used for I-ClaVI. See Table 22 in the results section for the scores and interpretation of results.

Table 18

Benchmarks Used for Interpretation of Modified Kappa

	Ranges	Interpretation
Polit et al., 2007, p.464	> 0.74	Excellent agreement
	0.60 - 0.74	Good agreement
	0.40 - 0.59	Fair agreement
	< 0.40	Poor agreement (item should be revised or dropped)
This study	> 0.80	Item retained
	0.60 - 0.79	Item retained but revised
	0.40 - 0.59	No items were in this bracket
	< 0.40	Item was dropped

Factorial validity was calculated by the percentage of experts that had agreed with the domain previously assigned to each item. Six items had 100% of agreement, 16 items 80% of agreement, 15 items had 60% of agreement, 15 items had 40% of agreement and 33 items had less than 20% of agreement. The results indicate that approximately 26% of items got 80% of agreement or more, whilst 73% had agreement below 80%. Although there are no criteria to determine what a good percentage of agreement is at this stage of the scale development (Rubio et al., 2003), it was recognised that experts had difficulty agreeing on the domains of loneliness previously assigned to each scale item. These results indicate the complexity of the construct of loneliness. The difficulty in reaching agreement when categorising items into the global, social, emotional, existential, experiential and positive loneliness, might have been due to overlapping emotions that can be experienced in each domain. Another issue might have been the lack of familiarity with the extended conceptualisation of loneliness presented for this study. The interpretation of the domains of loneliness could have been shaped by the experts' prior knowledge (or schemas) that can guide attention towards familiar information (i.e., social and emotional loneliness) and make unfamiliar concepts more difficult to

recognise (Barlett, 1995). Since the existential, experiential and positive domains of loneliness are less discussed, experts evaluating the items could have struggled to distinguish these domains as part of a multifaceted and more nuanced view of loneliness.

These are preliminary results. For understanding how items load significantly onto their intended factor, confirmatory factor analysis or exploratory factor analysis must be carried out (Hair et al., 2010), offering more robust measures and a definitive analysis of factorial validity. Nonetheless, these results were useful to refine the scale. Due to the number of experts, levels of agreement varied between zero, 20%, 40%, 60%, 80% and 100%. The items that had less than 40% of agreement (which means only two experts or less agreed with a domain), were further discussed with focus groups regarding their domains. Table 23 in the Results section, shows the items that had less than 40% of agreement amongst experts and the level of agreement on an alternative domain.

Candidate items were revised based on the results from the evaluations of the panel of experts. The items were reduced from 85 to 74 and were next presented to the second phase of content validity assessment.

Phase 3: Content Validity Assessed by Autistic People and Those Who Support Them

Once the evaluation from the panel of experts was completed and the candidate items were revised based on the results, autistic people and those who support them were invited to contribute their views. This phase of consultation was essential to address issues with relevance and clarity (wording) of items. Previous studies reinforced the importance of collaboration with autistic people when creating new measures or adapting standardised measures for autistic people (e.g. Grace et al. 2024; Love et al., 2025; McConachie et al., 2018; Rodgers et al., 2016) . Key recommendations include being transparent about partnerships, facilitating communication and power sharing, building trust, encouraging

participant capacitation, disseminating findings collaboratively and compensating participants fairly (Nicolaidis et al., 2019). Equally, guidance on scale development encourages the involvement of future scale users as a way of creating a measure that is both relevant and valid (Boateng et al., 2018; Haynes et al., 1995), as they are familiar with the construct through their own lived experience (Zamanzadeh et al., 2015). In this study, scale users include teachers, parents and professionals who support autistic young people and scale respondents include autistic young people.

Participants

Convenience sampling was used to recruit autistic young people (12 to 18 years old) and autistic adults (18 years old or older) to collaborate with the assessment content validity. The age range included adults at this stage as anyone with lived experience and those who support autistic people were sought. Recruitment was done by contacting gatekeepers by email, such as headteachers, inclusion managers and special needs coordinators (SENcos) in regular, independent and special schools and colleges in the UK. The email extended the invitation to parents of autistic young people and staff members working directly with autistic students, but groups were organised to have a balanced view. This meant groups always had an equal number or more of autistic people than non-autistic parents, and staff members. Recruitment was also done by contacting autistic people who had taken part in PPI groups for the other two studies of this thesis and had expressed an interest in being contacted again for other research projects. All participants were given an information sheet and asked to sign a consent form if they understood this and were willing to take part. Parental consent was given for people younger than 18 years old. All participants were asked for their assent at the start of the data collection sessions.

In total there were 22 collaborators, ranging from 12 to 50 years old (M=26.4, SD=10.51), 15 autistic and seven non-autistic people. Collaborators identified as female

(*n*=11), male (*n*=8) and non-binary (*n*=1). Two collaborators preferred not to identify with a gender. Collaborators described their ethnic background as, Asian (*n*=1), Asian British (*n*=1), Black British (*n*=2), Mixed or multi-ethnic (*n*=1), White European (*n*=2) and White British (*n*=14) and one preferred not to say their ethnicity. Two collaborators asked to be supported by members of staff and preferred to offer their views in a separate room. Two collaborators had to offer their views in one-to-one sessions due to exam commitments and due to other collaborators not being able to attend their preferred meeting times. Details about participants in focus groups can be seen in Table 19.

Data collection

To promote in-depth analyses of candidate items, there were a limited number of focus groups, each with a low number of collaborators and data collection tools were structured (Acocella & Cataldi, 2021). Collaborators were offered light refreshments during sessions and a £20 voucher for their time and contribution.

Meetings started with a briefing about the research project and previous findings, including how loneliness has been described by autistic young people and how this differs from usual ways of investigating loneliness. Participants were given a printed hand-out with information about the different domains of loneliness with examples and illustrations (Appendix F).

In total, 74 candidate items were grouped by domain (Global, Social, Emotional, Experiential, Existential and Positive Loneliness) and presented to participants one domain at a time (see example in Appendix G). The order in which the domains were presented varied across groups. Care was taken to ensure that each domain was reviewed at least once, with particular attention given to the recently added domains (Existential, Experiential and Positive Loneliness).

Table 19

Description of Participants who Took Part in Focus Groups for the Development of the ELSA

	Participants	Lived Experience	Gender	Age	Ethnicity
Group 1	Amara	Autistic	Female	24	Asian
	Liam*	Autistic	Male	20	Prefer not to say
	Rachael	Autistic	Female	24	White British
	Simon	Autistic	Male	23	White British
	Sophia*	Parent of autistic child; works with autistic young people in special provision	Female	50	Black British
	Tate	Autistic	Male	20	White British
Group 2	Andrew*	Works with autistic young people in special provision	Male	29	White British
	Barry	Works with autistic young people in special provision	Male	20	Prefer not to say
	Damian	Autistic; parent of autistic child; works with autistic young people in special provision	Male	38	Multi-ethnic
	Joseph	Autistic	Male	21	White British
	Maeve	Autistic	Not sure myself	24	White British
	Qamri*	Autistic	Female	24	White British
Group 3	Ella	Autistic	Non-binary	20	White British
	Lena	Wellbeing lead at special provision	Female	33	White British
	Nolan	Autistic	Prefer not to say	20	White British
	Riley	Studies with autistic peers at special provision	Female	17	White British
	Tara*	Autistic	Female	18	Black British
Group 4	John*	Autistic	Male	19	White British
Group 5	Beatrice	Autistic	Female	15	White British
	Emily	Autistic	Female	12	White European
	Hope	Parents of autistic child, teacher at selective secondary school, training to be SENDco	Female	38	White British
	Idalia	Parent of autistic child	Female	44	White European

*Liam asked to take part in a separate room with Sophia's support.

*Qamri requested to take part in a separate room with Andrew's support.

*Tara offered her views in a one-to-one session due to exam commitments.

*John offered his views in a one-to-one session due to other participants not attending at his preferred meeting time.

First, collaborators were asked to check the clarity of each item, identifying words they did not understand or items that could present issues with interpretation. Second, they were asked to judge how important each item was for a loneliness scale for autistic young people. They rated each item on a 5-point Likert scale (very important, important, relatively important, slightly important or not important) (Zamanzadeh et al., 2015). Some collaborators wrote notes and added observations about each item (see three examples in Appendix H), whilst others opted to talk about their perceptions. Discussions and notes included collaborators' justifications for their ideas and details about how to reword items. All discussions were audio recorded and transcribed.

Sessions were flexible and worked around the group's capacity and comfort. Focus group meetings lasted from 1.5 to 2 hours and were organised in different ways according to requests. Some groups preferred to work without interruptions, whilst others opted for scheduled breaks every half-hour. Similarly, the format of discussions varied across groups. In some groups, collaborators preferred to be given time to go through the items on their own first and then discuss their ideas with the group. In other meetings, items were read out loud and collaborators would add their views orally, item by item. This flexibility in pace and format formed part of the broader effort to embed inclusivity throughout the collaborative process.

At the end of each session, if participants were still willing to contribute, they were asked to choose a name for the scale. Nine participants agreed to take part. They were offered three options: a) ELSA (Experiences of Loneliness Scale for Autistic Young People) and b) PALS (Participatory Autistic Loneliness Scale) and c) any other name you can think of. Four participants voted on ELSA, two voted on PALS, one suggested SAVE (Scale for Valuing Emotions) and two said they could not choose one of the options or think of an alternative name. This was discussed with supervisors, and the name ELSA was adopted for the scale.

Qualitative data from collaborators' observations were extracted from the transcripts and organised in a spreadsheet alongside each corresponding item. Collating these views in one place was helpful when incorporating them into the refining and rewording of items. The structured evaluation of items with the 5-point Likert Scale provided quantitative data for the calculation of item impact score (I-IS), determining the items that were retained or eliminated (Zamanzadeh et al., 2015). This is explained in more detail in the Analysis section below. Once the scale was reduced, items were revised according to the suggestions given during discussions. Language was assessed once again with focus on filtering unnecessary words, adding examples where possible, improving conciseness and clarity, and being specific (Gaynor et al., 2020).

Analysis

Quantitative and qualitative data provided by focus groups were used to assess content validity of candidate items. Item Impact Score (I-IS) was calculated based on ratings of item importance and were interpreted according to benchmarks available in research literature. Items with scores equal or greater than 1.5 were retained, and items with scores smaller than 1.5 were eliminated (Lacasse et al., 2002; Zamanzadeh et al., 2015). Out of the 74 items presented to focus groups, 16 items had item impact scores smaller than 1.5 and were eliminated. See Table 24 for scores and interpretations in the Results section. The 58 items that were retained, were revised and changes suggested during focus groups were incorporated.

An example of how quantitative and qualitative results were used to improve the scale is provided by the item "I feel judged by others". This item had an I-IS of 3.36, which corresponds to a mean frequency of 80% and an importance mean of 4.2 on the 5-point Likert scale. Although these outcomes show that the item was consistently judged as important, the qualitative data indicated that the language used was too broad and vague, highlighting the

need for it to be more specific and therefore rephrased. Participants in focus groups were unsure if the question was related to situations when they are amongst people who are important to them or around strangers,

> *That [the words "other people"] throws me off. I don't know what you mean. I'm like, do you mean my family, my friends? Do you mean strangers? There's an entire difference between how do I feel if strangers judge me? I mean, I don't care. I'm never seeing them again. How I feel if my friends judge me, that's something we probably need to talk about.* (Maeve, 24)

The item was rephrased to "I feel judged by people in my community (e.g., at school, in my house, in my neighbourhood)". According to focus groups, adding examples could make concepts clearer to scale users and make some items easier to relate to. For this item, examples such as 'school', 'my house' and 'my neighbourhood' were added following suggestions given by participants.

Once the assessment of content validity was completed, the 58 items were once again assessed in conjunction with supervisors. It was noted some items were repetitive. Whilst item redundancy is useful to achieving internal reliability in survey design (Vetter & Cubbin, 2019), excessive repetition can negatively impact the quality of the data. Simms and Watson (2007) argue that surveys that are too repetitive can cause participants to become careless, thus providing low-quality responses. In addition, Clark and Watson (1995) warn that excessively high internal reliability may decrease the validity of a scale, as the items become too narrow as a compromise for showing that they measure the same construct. When items are highly correlated, it could mean they are measuring a narrow concept perfectly, rather than adequately capturing the breadth of the concept. Based on this, six items that appeared

too many times in the survey were eliminated. The eliminated items are shown in Table 25 in the Results section; 52 items were retained to be formatted for pre-testing.

Phase 4: Pre-testing

After the assessment of content validity by a panel of experts and focus groups with lived experience, 52 items were identified and constituted the draft scale of loneliness for autistic young people. The draft scale represented a conceptualisation of loneliness that included autistic perspectives and the scale items were distributed amongst six domains of loneliness that reflected different facets of the construct. Social and emotional loneliness reflecting unmet social needs; existential loneliness reflecting feeling different and not part of this world; experiential loneliness capturing feelings of being misunderstood; positive loneliness representing contentment with alternative forms of connection that do not involve relationships with other people; and global loneliness representing a general subjective experience of loneliness.

Pre-testing is a tool in scale development used to check if items are meaningful to the future scale respondents (Boateng et al., 2018). Pre-testing of the ELSA was carried out through cognitive interviews, which helped to identify and address issues with scale items. Beatty and Willis (2007) define cognitive interviewing as "the administration of draft survey questions while collecting additional verbal information about the survey responses" (p. 287).

Participants

Convenience sampling was used to recruit 15 autistic young people from 12 to 24 years old (M =16) to take part in three rounds of cognitive interviews (Table 20). Participants were recruited by contacting headteachers, SENCos, charity leaders, community group organisers and parents of children who have taken part in the two previous studies of this research project via email. Gatekeepers advertised the study within their communities and

parents got in touch via email to know more about the research and give their parental consent. All participants were asked for their assent at the start of the interview.

Following the principles of inclusive research adopted throughout the thesis, flexible modes of participation were employed to enable meaningful involvement and to minimise possible barriers. Interviews took place either at the participant's school or college, or remotely, via Teams. Online interviews were facilitated by Mentimeter. This digital tool allowed participants to answer to the survey in real time on their screens while on a Teams call.

Table 20

Participants Who Took Part in the Pre-Testing of the ELSA Through Three Rounds of Cognitive Interviews

Round	Name	Gender	Age	Ethnicity
Round 1	Emily	Female	12	White European
	Serena	Female	16	White British
	Ellie	Female	13	No answer
	Alexis	Female	15	White British
	Tristan	Male	13	White British
Round 2	Luca	Male	12	White British
	Jayden	Male	17	White British
	Simon	Male	22	White British
	Orla	Female	13	White British
	Abi	Female	15	White British
Round 3	Ocean	Female	19	White British
	Winter	Non-Binary	18	White British
	Declan	Male	17	White British
	Reese	Female	18	White British
	Danielle	Female	20	White British

Data Collection

To format the scale items into a survey, guidance on scale development and accessibility were followed (British Dyslexia Association, 2023; Leeds Autism AIM, 2021;

Scope, n.d.). This included, for example, using a sans serif font and appropriate spacing between items to make the survey easier to read. A systematic randomisation was used to distribute the 52 items. This meant that one item from each domain was picked at a time until all items were distributed throughout the scale. The randomisation of items has been recommended, especially for multidimensional measures (Şahin, 2021). Choosing to randomise items from different domains was a strategy used to minimise order and context effects (Brookes et al., 2018). In other words, the objective was for domains to receive equal attention by respondents.

Guidance for pre-testing new scales recommends 5 to 15 interviews to be conducted in rounds, interspersed with revision of the scale items (Beatty & Willis, 2007). Three rounds of five interviews were completed. During each round, a semi-structured interview protocol was followed (Appendix I). The questions used to facilitate participants' feedback focused on the vocabulary used, how well sentences were phrased, the easiness of responding to the questions, the range and type of responses, how certain words were interpreted and if participants felt the survey was too long or too short. Participants' behaviours were observed too and the semi-structured interview protocol listed non-verbal cues that could indicate problems with interpretation, cognitive overload or distress.

Sessions were structured to enable engagement and meaningful participation. Meetings started with the completion of a short demographic information form, followed by a brief explanation of the study. Young people were presented with an A4 sheet containing the instructions for the survey and an example of how to record their answers. The first version of the instructions of the survey can be seen in Figure 20. In these instructions participants were asked to rate how much each statement was true to their experiences by choosing one of four options in a Likert Scale (not true to my experience, mostly not true to my experience, mostly true to my experience and true to my experience).

The decision to use a Likert scale for responding to the survey was based on the feedback given by the panel of experts during the first phase of content validity assessment (Phase 2). A four-point Likert scale was selected for two reasons. First, removing the neutral option (e.g., 'neither agree nor disagree') may reduce response bias toward non-committal answers. Second, providing too many response options can contribute to cognitive overload. The four-point scale was therefore chosen to balance nuance in answers whilst maintaining adequate statistical sensitivity (Lozano et al., 2008). In addition to the Likert scale options, all items were presented with the options 'not applicable' and 'prefer not to answer'. At the end of each page of the first version of the survey, there was a space for participants to add comments. In addition to these decisions regarding response options, adaptations were made to enhance the accessibility of the survey. Each option of the Likert scale was accompanied by a visual icon, adapted from guidance on how to make surveys more accessible for autistic people (Nicolaidis et al., 2019).

Once participants were introduced to the survey format and response options, they were asked whether they understood the instructions and felt confident to respond to the initial five survey items. They were then invited to provide feedback on each item and subsequently completed the remaining items in batches of ten, providing feedback after each set. This process continued until all 52 items had been completed and feedback had been received for each item.

During sessions, participants were asked to walk the interviewer through their thought process when for example, they changed their mind, or when they took longer to respond a question. These behaviours at times indicated that the participant had to reflect for longer about an item in relation to their own experience. Other times, it meant that they had difficulties interpreting or understanding the scale item. All interviews were audio recorded and transcribed. Suggestions offered by participants were extracted from transcriptions,

collated into an Excel document and categorised as positive feedback or suggestion for refinement. These guided the changes made to items, to the survey layout and to the range of responses in between rounds of cognitive interviews. Changes on the scale items were reviewed by the research team after each round.

Analysis

This iterative process of collecting views, reviewing, and implementing feedback resulted in a series of revised versions of the scale across successive rounds of cognitive interviews. Consequently, each round of pre-testing had an updated version of the scale that reflected feedback from previous rounds. There were four versions in total. Version 1 (Appendix J) was used in the first round of interviews and was formatted following feedback from content validity assessments, guidance on how to develop measuring instruments and guidance on accessibility. Version 2 (Appendix K) was used in the second round of cognitive interviews and resulted from feedback suggested by participants in the first round of cognitive interviews. Version 3 (Appendix L), used in the third round of cognitive interviews incorporated suggestions given during the second round of cognitive interviews. The final version (Appendix M) included revisions following feedback received during the third round of pre-testing.

In summary, pre-testing of the ELSA was completed in three rounds comprising five cognitive interviews each. Before each round, the scale items and the survey layout were refined in response to suggestions provided by participants. Revisions have been grouped into two categories: (a) changes to the survey instructions and response options, and (b) refinements to the scale items. These are outlined in detail in the Results section.

Results

In this section, results of content validity assessments and pre-testing of the ELSA are presented under subheadings that reflect the study chronologically. The first two parts: (a) Content validity assessed by independent experts, and (b) Content validity assessed by autistic people and those who support them, offer statistical results used to refine and reduce scale items. The final section, (c) Pre-testing, details how qualitative data contributed by autistic young people were used to enhance the scale. This has been divided into two segments, starting with changes to the survey instructions and response range, followed by refinement of scale items.

Content Validity Assessed by Independent Experts

To determine content validity of the scale and of each candidate item, S-CVI/Ave, I-CVI , I-ClaVI were used. The S-CVI/Ave was 0.89, indicating good agreement among experts that the scale items were content valid overall (Polit & Beck, 2017). Out of the 85 candidate items presented to the panel of experts, 54 were retained ($k > 0.8$), 20 were revised and retained ($0.60 > k > 0.79$) and 11 were eliminated ($k < 0.4$) (Table 21).

Table 21

Assessment of the ELSA's Content Validity: Items Relevance Assessed by Panel of Experts

No.	Candidate Item	I-CVI*	Pc*	*k**	Interpretation
1	I often feel bored.	0	0.13	-0.14	Eliminate
2	Relationships are straight-forward and simple.	0.6	0.34	0.39	Eliminate
3	My anxiety makes it difficult for me to be social.	1	0.06	1.00	Appropriate
4	I enjoy online connections.	1	0.06	1.00	Appropriate
5	I enjoy watching or listening to people doing things.	1	0.06	1.00	Appropriate
6	When my senses are stimulated, I do not need other people.	1	0.06	1.00	Appropriate
7	I wish I had more adult support to make friends.	1	0.06	1.00	Appropriate
8	I enjoy being mentally engaged on my own.	1	0.06	1.00	Appropriate
9	I have people who understand what it is like to be me.	1	0.06	1.00	Appropriate
10	I fit in.	0.8	0.19	0.75	Revise

11	I feel I can communicate well with people.	0.8	0.19	0.75	Revise
12	I feel content with myself and other people.	0.4	0.34	0.09	Eliminate
13	I have people I like to be around.	0.8	0.19	0.75	Revise
14	I can make new friends.	0.8	0.19	0.75	Revise
15	I can be myself around people.	1	0.06	1.00	Appropriate
16	I feel I am included at my school / college.	1	0.06	1.00	Appropriate
17	I have people who I feel close to.	1	0.06	1.00	Appropriate
18	I feel low.	0.8	0.19	0.75	Revise
19	I know how to start conversations when I am in a group of people.	0.8	0.19	0.75	Revise
20	I have people who want to listen to me.	1	0.06	1.00	Appropriate
21	I enjoy time alone.	1	0.06	1.00	Appropriate
22	Sometimes I like being with others.	0.8	0.19	0.75	Revise
23	I feel judged by others.	0.8	0.19	0.75	Revise
24	I can connect meaningfully / best with people over WhatsApp or text messages.	0.6	0.34	0.39	Eliminate
25	I feel completely alone in the world.	1	0.06	1.00	Appropriate
26	My past negative experiences with people get in the way of new connections.	0.8	0.19	0.75	Revise
27	I prefer in-person connections.	0.8	0.19	0.75	Revise
28	I enjoy sharing spontaneous conversations with strangers.	0.6	0.34	0.39	Eliminate
29	I have enough people who make me feel good about myself.	1	0.06	1.00	Appropriate
30	Busy environments can make connections difficult.	0.8	0.13	0.77	Revise
31	I have people I feel comfortable with.	1	0.06	1.00	Appropriate
32	I find it difficult to show other people I want to connect with them.	1	0.06	1.00	Appropriate
33	I feel lonely.	1	0.06	1.00	Appropriate
34	I have personal interests that fulfil my need for people.	0.8	0.19	0.75	Revise
35	I find it difficult to connect with people out of school/college.	1	0.06	1.00	Appropriate
36	I am wanted around at school / college.	0.8	0.19	0.75	Revise
37	I know how to maintain conversations when I am in a group of people.	0.6	0.34	0.39	Eliminate
38	I feel I am accepted as I am.	1	0.06	1.00	Appropriate
39	I have people who understand my autistic needs.	1	0.06	1.00	Appropriate
40	I don’t need people when I am with my pets.	1	0.06	1.00	Appropriate
41	Being around people is enough for me not to feel lonely.	1	0.06	1.00	Appropriate
42	I connect with people online and that is enough for me.	1	0.06	1.00	Appropriate
43	I feel connected to someone when we have the same interests.	0.8	0.19	0.75	Revise
44	I have people who are interested in my wellbeing.	1	0.06	1.00	Appropriate
45	I have people I can talk to about things that bother me.	1	0.06	1.00	Appropriate
46	I have got lots of people in my life.	0.6	0.34	0.39	Eliminate
47	I feel I have people who are there for me if I need anything.	1	0.06	1.00	Appropriate
48	I feel misunderstood.	1	0.06	1.00	Appropriate
49	I enjoy doing solo activities.	0.8	0.19	0.75	Revise
50	I hide my true self most of the time.	1	0.06	1.00	Appropriate
51	I don’t feel the need to be around people that often.	1	0.06	1.00	Appropriate

52	I enjoy talking to imaginary people.	0.6	0.34	0.39	Eliminate
53	I am well-liked by people in my school / college.	0.8	0.19	0.75	Revise
54	I find it easy to deal with people.	0.6	0.34	0.39	Eliminate
55	I find it difficult to be social	0.8	0.19	0.75	Revise
56	I would like to have more people to talk to everyday.	1	0.06	1.00	Appropriate
57	I wish I had more in-person connections.	1	0.06	1.00	Appropriate
58	I have people with similar interests to mine.	1	0.06	1.00	Appropriate
59	I enjoy using my imagination.	0.6	0.34	0.39	Eliminate
60	I have people who care about me.	1	0.06	1.00	Appropriate
61	Positive everyday exchanges make me feel I belong.	1	0.06	1.00	Appropriate
62	I have people who “get me.”	1	0.06	1.00	Appropriate
63	I have people who can give me emotional support.	1	0.06	1.00	Appropriate
64	I like feeling lonely.	0.8	0.19	0.75	Revise
65	I have places where I can be myself.	1	0.06	1.00	Appropriate
66	I feel like withdrawing from social activities.	1	0.06	1.00	Appropriate
67	I can connect to fictional characters (in movies, books, series, etc.).	0.8	0.19	0.75	Revise
68	I have pets that are like friends.	1	0.06	1.00	Appropriate
69	I wish I had more friends.	1	0.06	1.00	Appropriate
70	I have important objects that help when I feel lonely.	1	0.06	1.00	Appropriate
71	Sometimes, I like being on my own.	1	0.06	1.00	Appropriate
72	I am well-liked by people who are important to me.	1	0.06	1.00	Appropriate
73	I have people with whom I have deep connections with.	1	0.06	1.00	Appropriate
74	I feel rejected.	1	0.06	1.00	Appropriate
75	I feel empty.	1	0.06	1.00	Appropriate
76	I find it difficult to connect with people at school/college.	1	0.06	1.00	Appropriate
77	I like being on my own in safe spaces.	1	0.06	1.00	Appropriate
78	I enjoy being physically active on my own.	0.6	0.34	0.39	Eliminate
79	I rely on my family for close relationships.	1	0.06	1.00	Appropriate
80	I feel different from other people my age.	1	0.06	1.00	Appropriate
81	I have people I can talk to and have a good time with.	1	0.06	1.00	Appropriate
82	I have people who understand how I experience the world.	1	0.06	1.00	Appropriate
83	I like talking to objects.	0.8	0.19	0.75	Revise
84	I feel there are other people like me.	1	0.06	1.00	Appropriate
85	I have people with whom I can share day-to-day-activities.	1	0.06	1.00	Appropriate

*I-CVI = Index Content Validity; Pc = Probability of chance agreement; *k* = modified Kappa

Out of the 85 items 67 were judged to be clear ($k > 0.8$), 13 items needed minor revisions ($0.60 > k > 0.79$) and 5 items needed major revisions ($k < 0.4$) Findings regarding clarity were largely consistent with those regarding relevance. Of the 18 items that needed minor and major revisions under the clarity assessment, thirteen were either eliminated or similarly identified as needing revision for relevance (Table 22).

Table 22

Assessment of the ELSA's Content Validity: Items Clarity Assessed by Panel of Experts

No.	Candidate Item	I-ClaVI*	Pc*	*k**	Interpretation
1	I often feel bored.	1	0.13	1.00	Appropriate
2	Relationships are straight-forward and simple.	0.8	0.19	0.75	Revise
3	My anxiety makes it difficult for me to be social.	1	0.06	1.00	Appropriate
4	I enjoy online connections.	1	0.06	1.00	Appropriate
5	I enjoy watching or listening to people doing things.	1	0.06	1.00	Appropriate
6	When my senses are stimulated, I do not need other people.	0.8	0.19	0.75	Revise
7	I wish I had more adult support to make friends.	1	0.06	1.00	Appropriate
8	I enjoy being mentally engaged on my own.	1	0.06	1.00	Appropriate
9	I have people who understand what it is like to be me.	1	0.06	1.00	Appropriate
10	I fit in.	1	0.19	1.00	Appropriate
11	I feel I can communicate well with people.	1	0.06	1.00	Appropriate
12	I feel content with myself and other people.	0.4	0.34	0.09	Major revision
13	I have people I like to be around.	0.8	0.19	0.75	Revise
14	I can make new friends.	1	0.06	1.00	Appropriate
15	I can be myself around people.	1	0.06	1.00	Appropriate
16	I feel I am included at my school / college.	1	0.19	1.00	Appropriate
17	I have people who I feel close to.	1	0.06	1.00	Appropriate
18	I feel low.	0.6	0.34	0.39	Major revision
19	I know how to start conversations when I am in a group of people.	1	0.06	1.00	Appropriate
20	I have people who want to listen to me.	1	0.06	1.00	Appropriate
21	I enjoy time alone.	1	0.06	1.00	Appropriate
22	Sometimes I like being with others.	1	0.06	1.00	Appropriate
23	I feel judged by others.	1	0.06	1.00	Appropriate
24	I can connect meaningfully / best with people over WhatsApp or text messages.	0.8	0.19	0.75	Revise
25	I feel completely alone in the world.	1	0.06	1.00	Appropriate
26	My past negative experiences with people get in the way of new connections.	1	0.06	1.00	Appropriate
27	I prefer in-person connections.	1	0.06	1.00	Appropriate
28	I enjoy sharing spontaneous conversations with strangers.	1	0.06	1.00	Appropriate
29	I have enough people who make me feel good about myself.	1	0.06	1.00	Appropriate
30	Busy environments can make connections difficult.	0.8	0.13	0.77	Revise
31	I have people I feel comfortable with.	1	0.06	1.00	Appropriate
32	I find it difficult to show other people I want to connect with them.	1	0.06	1.00	Appropriate
33	I feel lonely.	1	0.06	1.00	Appropriate

34	I have personal interests that fulfil my need for people.	0.6	0.34	0.39	Major revision
35	I find it difficult to connect with people out of school/college.	1	0.06	1.00	Appropriate
36	I am wanted around at school / college.	0.6	0.34	0.39	Major revision
37	I know how to maintain conversations when I am in a group of people.	1	0.06	1.00	Appropriate
38	I feel I am accepted as I am.	1	0.06	0.75	Appropriate
39	I have people who understand my autistic needs.	1	0.06	1.00	Appropriate
40	I don't need people when I am with my pets.	0.6	0.34	1.00	Major revision
41	Being around people is enough for me not to feel lonely.	1	0.06	1.00	Appropriate
42	I connect with people online and that is enough for me.	0.8	0.19	1.00	Revise
43	I feel connected to someone when we have the same interests.	1	0.06	1.00	Appropriate
44	I have people who are interested in my wellbeing.	1	0.06	1.00	Appropriate
45	I have people I can talk to about things that bother me.	1	0.06	1.00	Appropriate
46	I have got lots of people in my life.	1	0.06	1.00	Appropriate
47	I feel I have people who are there for me if I need anything.	1	0.06	1.00	Appropriate
48	I feel misunderstood.	1	0.06	1.00	Appropriate
49	I enjoy doing solo activities.	1	0.06	1.00	Appropriate
50	I hide my true self most of the time.	1	0.06	1.00	Appropriate
51	I don't feel the need to be around people that often.	1	0.06	1.00	Appropriate
52	I enjoy talking to imaginary people.	0.8	0.19	0.75	Revise
53	I am well-liked by people in my school / college.	0.8	0.19	0.75	Revise
54	I find it easy to deal with people.	0.8	0.19	0.75	Revise
55	I find it difficult to be social	1	0.06	1.00	Appropriate
56	I would like to have more people to talk to everyday.	1	0.06	1.00	Appropriate
57	I wish I had more in-person connections.	1	0.06	1.00	Appropriate
58	I have people with similar interests to mine.	1	0.06	1.00	Appropriate
59	I enjoy using my imagination.	1	0.06	1.00	Appropriate
60	I have people who care about me.	1	0.06	1.00	Appropriate
61	Positive everyday exchanges make me feel I belong.	1	0.06	1.00	Appropriate
62	I have people who "get me."	1	0.06	1.00	Appropriate
63	I have people who can give me emotional support.	1	0.06	1.00	Appropriate
64	I like feeling lonely.	1	0.06	1.00	Appropriate
65	I have places where I can be myself.	0.8	0.19	0.75	Revise
66	I feel like withdrawing from social activities.	1	0.06	1.00	Appropriate
67	I can connect to fictional characters (in movies, books, series, etc.).	1	0.06	1.00	Appropriate
68	I have pets that are like friends.	1	0.06	1.00	Appropriate
69	I wish I had more friends.	1	0.06	1.00	Appropriate
70	I have important objects that help when I feel lonely.	1	0.06	1.00	Appropriate

71	Sometimes, I like being on my own.	1	0.06	1.00	Appropriate
72	I am well-liked by people who are important to me.	1	0.06	1.00	Appropriate
73	I have people with whom I have deep connections with.	1	0.06	1.00	Appropriate
74	I feel rejected.	1	0.06	1.00	Appropriate
75	I feel empty.	1	0.06	1.00	Appropriate
76	I find it difficult to connect with people at school/college.	1	0.06	1.00	Appropriate
77	I like being on my own in safe spaces.	1	0.06	1.00	Appropriate
78	I enjoy being physically active on my own.	0.8	0.19	0.75	Revise
79	I rely on my family for close relationships.	1	0.06	1.00	Appropriate
80	I feel different from other people my age.	1	0.06	1.00	Appropriate
81	I have people I can talk to and have a good time with.	0.8	0.19	0.75	Revise
82	I have people who understand how I experience the world.	1	0.06	1.00	Appropriate
83	I like talking to objects.	0.8	0.19	0.75	Revise
84	I feel there are other people like me.	1	0.06	1.00	Appropriate
85	I have people with whom I can share day-to-day-activities.	1	0.06	1.00	Appropriate

*I-ClaVI = Item Clarity Validity Index; Pc = Probability of chance agreement; *k* = modified Kappa

It was difficult to establish factorial validity at this stage, potentially reflecting the panel's limited familiarity with the less discussed facets of loneliness. Results were used to inform discussions with focus groups. Table 23 shows items that had less than 40% of agreement amongst experts on the original domains assigned and the percentage of agreement on a new domain.

Table 23

Candidate Items That Had Low Agreement on the Evaluation of the Domains of Loneliness

Item	Domain originally assigned	% of Agreement	Alternative domain	% of Agreement
I enjoy online connections.	Positive	0	Social	60%
I enjoy watching or listening to people doing things.	Positive	20%	Experiential	40%
I feel I am included at my school / college.	Existential	0	Social	80%
I prefer in-person connections.	Positive	0	Global	40%
I have enough people who make me feel good about myself.	Existential	0	Social	60%

I find it difficult to show other people I want to connect with them.	Social	0	Experiential	60%
Being around people is enough for me not to feel lonely.	Positive	0	Social	60%
I connect with people online and that is enough for me.	Positive	20%	Social	60%
I wish I had more in-person connections.	Positive	0	Social	60%
I have people with similar interests to mine.	Existential	20%	Experiential	40%
Positive everyday exchanges make me feel I belong.	Positive	0	Global	60%
I can connect to fictional characters (in movies, books, series, etc.).	Positive	20%	Existential	40%
I have important objects that help when I feel lonely.	Positive	20%	Global	40%
I feel rejected.	Existential	0	Global	60%
I rely on my family for close relationships.	Emotional	40%	Social	60%

Regarding the type of response that would suit the scale, the panel of experts during content validity assessment voted unanimously for using a Likert scale. One expert also voted for a Likert scale represented by icons. All experts commented on the importance of consulting with scale users on this regard, pointing out that icons might work with younger users and that autistic young people might prefer a visual type of response. Visual icons were added to the version presented at cognitive interviews to autistic young people to gather more information from scale users.

Content Validity Assessed by Autistic People and Those Who Support Them

To determine content validity during this phase of assessment, I-IS was used, together with qualitative data extracted from discussions with focus groups. Participants evaluated 74 candidate scale items; 16 items had I-IS smaller than 1.5 and were eliminated. The 58 items that were retained, were revised and changes suggested during focus groups were incorporated (Table 24).

Table 24

Content Validity of the ELSA Assessed by Autistic People and Those Who Support Them

Domain		Candidate Item	No. of evaluations	I-IS	Results
Social Loneliness	1	I have enough people who make me feel good about myself.	10	2.59	Include
	2	I have people I feel comfortable with.	10	3.28	Include
	3	I find it difficult to connect with people out of school/college.	10	2.73	Include
	4	Being around people is enough for me not to feel lonely.	10	1.70	Include
	5	I connect with people online and that is enough for me.	10	1.16	Eliminate
	6	I am liked by people who are my age.	10	0.93	Eliminate
	7	I enjoy online connections.	10	2.10	Include
	8	I wish I had more adult support to make friends.	10	1.32	Eliminate
	9	I have people I like to be around.	10	3.28	Include
	10	I can make new friends.	10	3.96	Include
	11	I feel I am included at by people who are my age.	10	2.94	Include
	12	I know how to start conversations when I am in a group of people.	10	3.28	Include
	13	I find it difficult to be social.	10	3.28	Include
	14	I would like to have more people to talk to everyday.	10	2.22	Include
	15	I wish I had more in-person connections.	10	1.40	Eliminate
	16	I wish I had more friends.	10	1.75	Include
	17	I find it difficult to connect with who are the same age as I am.	10	2.19	Include
	18	I have people I can talk to and have a good tie with.	10	3.96	Include
	19	I have people with whom I can share day-to-day activities.	10	3.87	Include
	20	I rely on my family for close relationships.	10	1.14	Eliminate
	21	I have people who care about me.	15	3.13	Include

Domain		Candidate Item	No. of evaluations	I-IS	Results
	22	I have people who can give me emotional support.	15	3.54	Include
	23	I am liked by people who are important to me.	15	3.47	Include
	24	I have people with whom I have deep connections.	15	4.05	Include
Emotional	25	I have people who I feel close to.	15	4.67	Include
Loneliness	26	I have people who want to listen to me.	15	4.29	Include
	27	I have people who are interested in my wellbeing.	15	3.81	Include
	28	I have people I can talk to about things that bother me.	15	4.29	Include
	29	I feel I have people who are there for me if I need anything.	15	3.98	Include
Global	30	I feel emotionally low.	11	1.92	Include
Loneliness	31	I feel lonely.	11	1.86	Include
	32	Positive everyday exchanges make me feel I belong.	11	1.03	Eliminate
	33	I feel rejected.	11	0.85	Eliminate
	34	I feel empty.	11	1.33	Eliminate
Experiential Loneliness	35	Busy environments, such as crowded places or places with a lot of visual information can make connections difficult.	16	1.69	Include
	36	I find it difficult to show other people I want to connect with them.	16	0.86	Eliminate
	37	I have people who understand my autistic needs.	16	0.71	Eliminate
	38	I have people who understand how I experience the world.	16	0.84	Eliminate
	39	My anxiety makes it difficult for me to be social.	16	1.21	Eliminate
	40	I have people who understand what it is like to be me.	16	1.41	Eliminate
	41	I feel I can communicate well with people.	16	1.64	Include

Domain		Candidate Item	No. of evaluations	I-IS	Results
	42	My past negative experiences with people get in the way of new connections.	16	0.88	Eliminate
Existential Loneliness	43	I feel misunderstood.	20	3.59	Include
	44	I hide my true self most of the time.	20	2.59	Include
	45	I have people with similar interests to mine.	20	2.87	Include
	46	I have people who "get me"	20	3.72	Include
	47	I have places where I can be myself	20	3.91	Include
	48	I feel like withdrawing from social activities.	20	1.83	Include
	49	I feel different from other people my age.	20	2.07	Include
	50	I feel there are other people like me.	20	2.46	Include
	51	I fit with others.	20	2.01	Include
	52	I can be myself around people.	20	2.96	Include
	53	I feel judged by others.	20	3.36	Include
	54	I feel completely alone in the world.	20	3.81	Include
	55	I feel that others want my company.	20	2.83	Include
	56	I feel I am accepted as I am.	20	2.96	Include
	57	I feel connected to someone when we have the same interests.	20	3.10	Include
Positive Loneliness	58	I like feeling lonely. / I like being alone.	16	1.81	Include
	59	I feel less lonely when I connect to fictional characters (in movies, books, series, etc.)	16	3.40	Include
	60	I have pets that are like friends.	16	3.20	Include
	61	I have important objects that help when I feel lonely.	16	2.58	Include
	62	Sometimes, I like being on my own.	16	1.96	Include
	63	I like being on my own in safe spaces.	16	2.79	Include
	64	Talking to objects such as teddy bears, toys, etc., make me feel less lonely.	16	0.47	Eliminate
	65	I prefer in-person connections.	18	1.72	Include
	66	I have personal interests that are more important to me than my need for people.	18	2.30	Include
	67	I don't need people when I am with my pets or other animals.	18	2.16	Include

Domain		Candidate Item	No. of evaluations	I-IS	Results
	68	I enjoy doing activities by myself.	18	1.56	Include
	69	I don't feel the need to be around people that often.	18	2.86	Include
	70	I feel less lonely when I can be an observer (e.g., watching people playing a game or have a conversation; or listen to family members go about their day).	18	1.41	Eliminate
	71	When my senses are stimulated, I do not need other people.	18	2.08	Include
	72	I enjoy being mentally engaged on my own.	18	1.84	Include
	73	I enjoy time alone.	18	2.21	Include
	74	I like being with others.	18	2.53	Include

The 58 items retained after collaboration with focus groups were again evaluated by the main researcher and supervision team. Six items were considered too repetitive and were eliminated to maintain the quality (Simms & Watson, 2007) and validity (Clark & Watson, 1995) of the scale, resulting in 52 retained items (Table 25).

Table 25

Redundant Candidate Items Eliminated from the ELSA by Main Researcher and Supervisory Team

Domain	Item
Emotional	I feel I have people who are there for me if I need anything.
Existential	I have people with similar interests to mine.
Positive	Sometimes, I like being on my own.
Positive	I don't need people when I am with my pets or other animals.
Positive	I enjoy being mentally engaged on my own.
Positive	I like being with others.

Pre-testing

This section shows how the survey evolved after each round of consultation and details how qualitative data contributed by autistic young people were used to refine scale items. The changes are outlined in subsections that include (a) changes to the survey instructions and response options, and (b) refinements to the scale items.

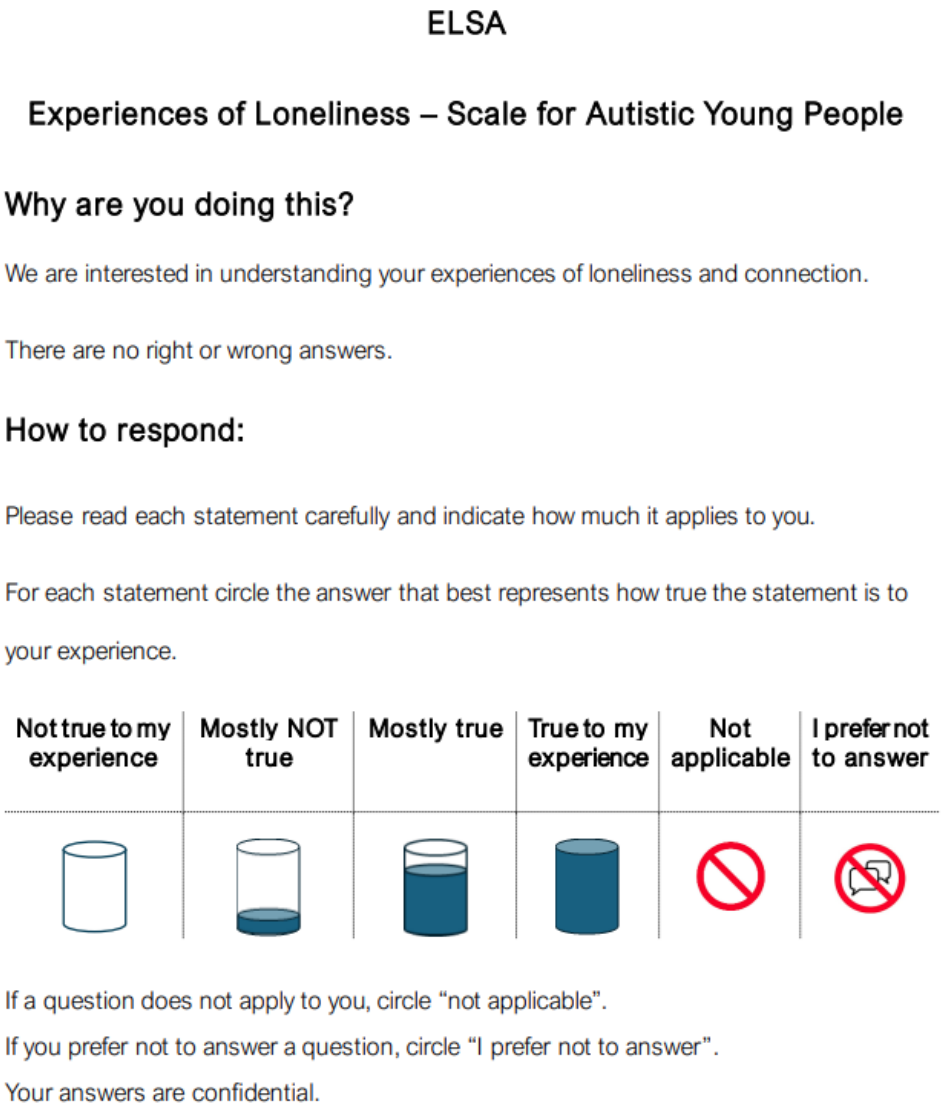
a) Changes to the Survey Instructions and Response Options

All participants in the first round of pre-testing thought the instructions were clear and affirmed being confident in what they were asked to do. Figure 20 shows the first version of the survey instructions shared with autistic young people pre-testing the ELSA. One participant was unsure whether to base his answers on his past or present experiences, "I was thinking about the past, but I was also thinking about... I didn't know if it was about the past or now" (Tristan, 13). To address this, a sentence guiding participants to base their answers on how they were feeling presently was added to the instructions on the subsequent version of the ELSA (Figure 21).

Feedback regarding the use of visual icons coupled with verbal cues was mostly positive. Participants in the first round of interviews said that having the visual cues helped them to interpret the response options: "Yeah, they are quite helpful" (Tristan, 13); "I like how they're like in the jars because that visualises it better" (Emily, 12); "It's a good way of visualising it" (Serena, 16). Ellie (12) and Alexis (15) did not use the icons and focused more on the verbal cues. They agreed that although it did not help them, they could be useful to other respondents, "No, I just sort of ignored the drawings. I don't really think drawings are helpful. I mean, I get why some people might need drawings but for me, it feels like quite a simple idea" (Alexis, 15).

Figure 20

First Version of the Survey Instructions Shared with Participants Pre-Testing the ELSA



Similar evaluations came from different participants in the second and third rounds of pre-testing, who reacted positively to the use of visual icons to illustrate the response options. Many thought they were valuable, "I think it's a nice visual" (Abi, 15, Round 2); "They are good" (Declan, 27, Round 3); "They are useful" (Danielle, 20, Round 3); and "Icons are helpful" (Winter, 18, Round 3). As in the first round, participants who felt they did not need the icons to support the interpretation of the responses, agreed they should be retained, as "I

think it might help other people more" (Ocean, 19, Round 3). Some highlighted that although not needed the icons did not bother them, "They're just kind of there, I can, I can have them but it's not like I necessarily need them" (Luca, 12, Round 2). Simon (22, Round 2) suggested that each cylinder could have a different colour, "maybe green for like true and red for not true". After considering and discussing this suggestion with supervisors, it was decided that adding different colours to each icon could possibly influence responses. Green can be commonly associated with what is correct and red with what is wrong. Adopting one colour to all icons was considered a consistent and neutral approach, therefore no colour changes were made.

All participants were asked about the general layout of the survey and most evaluated it positively, with Declan (17, Round 3) describing it as "very good, very easy to follow". Danielle (20, Round 3) and Reese (18, Round 3) agreed that the layout worked well. Jayden (17, Round 2) noted that the design did not feel infantilising compared to other surveys he had completed "It's clear. It gives you your visuals, but it's not, it doesn't look like it was made for a child. This isn't offensive".

The font and spacing between scale items were mostly approved throughout all rounds of pre-testing, "It was nice. It doesn't feel like overwhelming cause it's just a few questions in each page" (Winter, 18, Round 3); "I like the font" (Simon, 22, Round 2); "Yeah, I think they were good" (Emily, 12, Round 1); "Good size. I like the bold" (Ellie, 13, Round 1). In contrast, Luca (12, Round 2) had a more neutral perception of the layout saying, "it just looks like a normal questionnaire" and Simon (22, Round 2) felt there could be "too many questions in one page". This issue was addressed on the third version of the scale (Figure 22) by adding a comment box to every page and reducing the number of questions per page from five to four.

Alexis (15, Round 1) said she did not like the font used and suggested that the colours could be improved “There's like nothing wrong with them. But there are like nicer colours”. A lighter palette of colours was adopted for the second version (Figure 21). Her suggestion of changing the font was not taken forward as she would have preferred a “curvy one”. Although research has found no significant differences in legibility and comprehension of texts printed in serif or sans serif fonts (Richardson, 2022), several advocacy groups (British Dyslexia Association, 2023; Leeds Autism AIM, 2021; Scope, n.d.) and government guidance (Department for Work and Pensions, n.d.) recommend the use of sans serif fonts to improve accessibility and readability. The font was kept the same throughout all rounds of revision.

The range and type of responses received substantial feedback from participants during the first round of interviews. Although the four-point Likert scale was chosen specifically to avoid cognitive overload and to make options simpler, all participants in the first round of pre-testing missed a middle point. Alexis (15) pointed the need for more response options even before she started answering the survey, "I don't know what the questions are, but I'd put a 50-50 [option]". Serena (16) observed that having a middle point would have helped her to choose a more adequate response for each item, "I think it would have been helpful to have like a middle response possibly. Some of them I was really debating between mostly not true and mostly true, and I just wouldn't define it completely as either". Ellie (13) tried to work around the lack of an adequate option by adapting her answers, “Can I put a mark in between [the options] or does it have to be one or the other?". Later she suggested how the options could be expanded by adding a response option between ‘mostly NOT true’ and ‘mostly true’, "I feel like it needs to be, like, a box in between here" (Ellie, 13). To address this limitation, a middle point was added to the response options with

the suggested words ‘kind of true to my experience’, accompanied by an icon that looked half full (Figure 21).

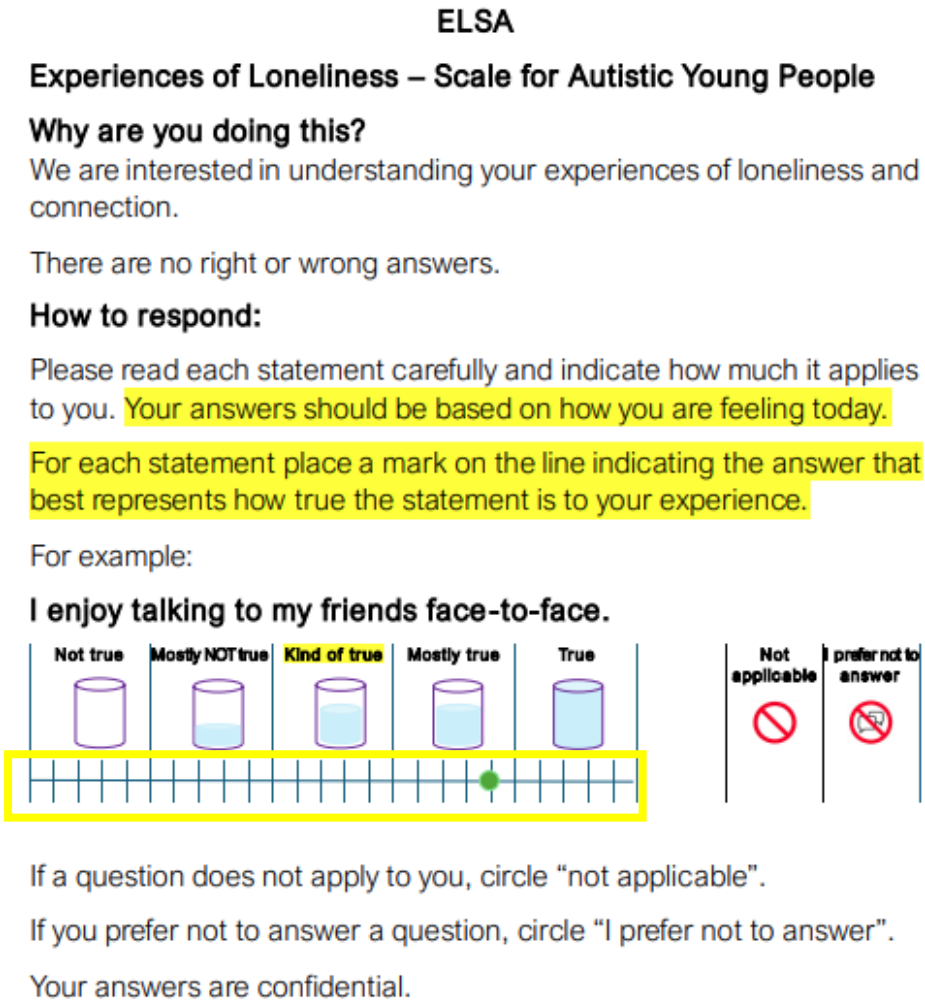
Four participants commented on the difficulty of choosing one option only and three offered suggestions on how to improve this. Emily (12) observed that "There is always a big gap between false and true”. She suggested using a slider or a continuum line ranging from ‘not true to my experience’ to ‘true to my experience’, allowing respondents to place a mark at the point that best reflected their experience. Alexis (15) added to that idea saying that adding nuance in how to record answers would help with representing experiences more closely, "there will be times where it's not 100% [true to my experience]". Alexis (15) also expressed her preference for a slider or a continuum line, "If you had points on it, like 1, 2, 3, 4, 5, 6, 7, like 1 to 10. Yeah. I think that'd be good." Ellie (13) supported the idea of amplifying the range of response options by dividing the sections with subsegments, "Just have a little bit like in between each one”. To address the concerns related to the lack of nuance of the response options, a line with segments was added under the icons and survey instructions were adapted to guide respondents to choose a place on the line that best represented their experiences. An example was included to the instructions for clarity. All changes made to the survey instructions, layout and range of responses, guided by the feedback received during the first round of pre-testing, have been highlighted in yellow on Figure 21.

The changes made to the range of options during the first round were well accepted by the young people who took part in the second round of pre-testing. Jayden (17) and Luca (12) agreed that the five response options made sense to them, with Jayden (17) highlighting the benefits of having a range of responses within each option, "Personally, for me, it's better. Sometimes it isn't just one or the other. And sometimes it's a mix." Participants in the third round of interviews noted how the variety of options helped to represent their experiences, “It

helps because it's not specific answers... you can say it's kind of in between. It's more precise. I like it", (Declan, 17); "It (pause) makes less of a barrier between the two, you know, different, um, like, answers because sometimes it can be limited (...) usually they don't have so many options in between" (Ocean, 19). Danielle (20) characterised the range of options as "just right".

Figure 21

Changes Made to the Survey Instructions and to the Range of Responses for Round Two of Pre-Testing of the ELSA



Despite the modified range of responses being positively evaluated by many participants, the line with segments proposed for recording responses was critiqued during the second round of pre-testing. Simon (22) placed many of his answers in between markers and suggested a digital version that would allow participants to place their responses at any point on the line ranging from ‘not true to my experience’ to ‘true to my experience’. Simon’s idea will be considered again when the scale is furthered developed, and a digital version is planned for dissemination. The visual aspect of the line used to record responses was also discussed by Abi (15) who did not like how it looked, “I feel like the lines are just a bit off-putting". She suggested swapping the segments for circles that could be ticked or shaded (Figure 22).

For the subsequent version of the ELSA, the layout suggested by Abi (15) was adopted and the survey instructions were adjusted to reflect this change. Having circles instead of lines, visually reduces the gaps between responses. This new design was positively evaluated by some participants in the third round of pre-testing. Danielle (20) felt the new design was “straightforward” and Declan (17) commented that the circles on the line “definitely work”. Ocean (19) said that the way she was asked to record her answers “was fine”, but Winter (18) commented that the “circles are very close together and it's hard to separate them." To address this, the size of the circles was slightly increased for the final version of the ELSA (Appendix M).

Reese (18, round 3) was the only participant who said she preferred to choose one of the five response options (indicated by the word cues) rather than placing her answer within the range, "I feel like maybe I prefer to just put a tick on the one." However, when she answered the questions, her ticks were not placed all in the middle of each option, but at different positions in each section, mirroring the range below. For example, for the question “I would like to have more friends to interact with every day”, she ticked the option ‘mostly

NOT true' but very close to the line dividing this option from 'Not true'. The statement "I feel happy when doing activities by myself" was 'Mostly true' for Reese, and the tick was placed just over the circle before the line that separates this option from 'True'. This was interpreted as her using her own range to answer to the questions. This was recorded as a point to be observed when the scale is further developed and tested more widely.

The version used for the third round of pre-testing (Figure 22) saw a change in the font size for the word cues, suggested by Jayden (17), and the return of a box for comments at the end of every page, suggested by Abi (15). The first version of the survey included spaces for comments, but as they were not used by any participants during the first round, they were removed for the second round of pre-testing. Although Abi (15) did not personally add any comments, she considered this could be useful to other participants, which supervisors agreed with. A slight change in design was made to the box of comments for the final version (Appendix M) making it more visible than it was before. Finally, numbers were included under the response line to illustrate options ranging from 'not true to my experience' = 0 to 'true to my experience' = 5. Figure 22 shows all the changes highlighted in yellow.

b) Revisions to the Scale Items

All participants, in the three rounds of pre-testing, evaluated the scale items as relevant and generally easy to understand. Serena (16, Round 1) said she saw the reasoning behind the questions "They all link to different parts of how I feel loneliness". Reese (18, Round 3), Ocean (19, Round 3) and Simon (22, Round 2) thought the questions were mostly easy to understand, relevant and interesting: "I think it was easy enough" (Reese); "I think they are mostly applicable" (Ocean); "…they are like interesting questions" (Simon). Declan (17, Round 3) enjoyed responding to the survey, "This is quite fun, this. Because I'm thinking about myself". In contrast, Simon (22, Round 3) said he felt somewhat upset after answering the survey, "I'd say like, a little bit sad to be honest."

Figure 22

Changes Made to the Survey Instructions and to the Range of Responses for Round Three of Pre-Testing of the ELSA

ELSA

Experiences of Loneliness – Scale for Autistic Young People

Why are you doing this?

We are interested in understanding your experiences of loneliness and connection.

There are no right or wrong answers.

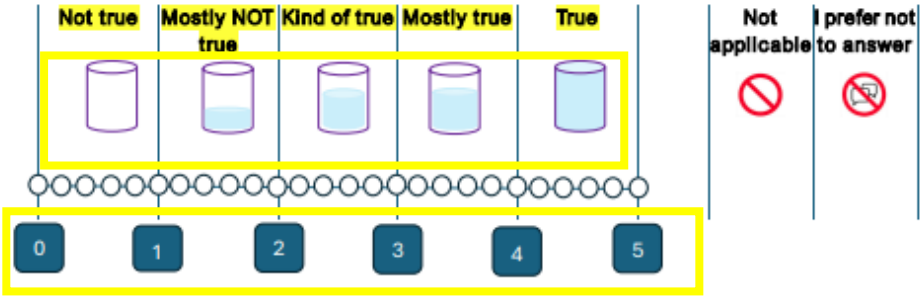
How to respond:

Please read each statement carefully and indicate how much it applies to you. Your answers should be based on how you are feeling today.

For each statement shade a circle on the line indicating how true the statement is to your experience. The start on the left is equivalent to not true (0) and the end on the right is equivalent to very true (5).

For example:

I enjoy talking to my friends face-to-face.



If a question does not apply to you, circle "not applicable".

If you prefer not to answer a question, circle "I prefer not to answer".

The grey boxes at the end of the page are a space for any reflections, comments, doodles or drawings you might want to add.

Your answers are confidential.

Some participants made comments about the length of scale items. Jayden (17, Round 2) and Simon (22, Round 2) described items 26 to 35 as “a bit wordy”. In the version presented to Simon and Jayden, items 26 to 35 included an average of approximately 12 words per item. Blocks of 10 questions at the start of the survey had slightly lower average word counts. Items 1 to10 had an average of approximately 10 words per item and items 11 to 20, nine words per item. The block of 10 questions immediately after the one identified by the participants (37 to 46) had an average of approximately 10 words per item. Although the differences in the average word count were small, it was noticed that the average word count increased toward the end of the survey. A redistribution of items was planned (Table 26), aiming to have a more balanced word count throughout the survey. This alteration was based on the assumption that motivation can be higher at the beginning of the task but starts dropping as the task progresses (Streiner et al., 2015). Having an increased word count per item towards the end of the survey could be making it more difficult for respondents to keep focused or motivated.

Table 26

Redistribution of Scale Items After the Second Round of Pre-Testing of the ELSA

Item no.	Item	Swapped for	Item no.	Item
4	I feel misunderstood.	⇄	44	I feel I have to hide my true self most of the time.
7	I feel that others want my company.	⇄	27	I have enough people in real life who make me feel good about myself.
8	I like being on my own in safe spaces.	⇄	33	I feel less lonely when I connect to fictional characters (in movies, books, TV shows, games, etc.)
11	I like being with people I am familiar with.	⇄	45	I have important objects that help when I feel lonely.
15	I prefer engaging with personal interests than being with other people.	⇄	39	I have pets that are like friends.

19	Good and positive sensory stimulation makes me feel less lonely. Total Word Count: 49	⇄	52	Being alone is important to me. Total Word Count: 67

After the third round of interviews, when formatting the final version of the ELSA, the redistribution of scale items was reviewed once again due to the rewording of some items. A few items were swapped to avoid longer word counts towards the end of the survey (Table 27).

Table 27

Redistribution of Items After Round 3 of Pre-Testing

Item no.	**Item**	**Swapped for**	**Item no.**	**Item**
3	I have people who care about me.	⇄	36	I have people who can give me emotional support.
18	I have deep personal connections.	⇄	52	Good and positive sensory stimulation makes me feel less lonely (e.g., cuddling a soft toy, using a weighted blanket, being in a darkened room, listening to soothing sounds, etc.).
23	I have people I can talk to and have a good time with. Total Word Count: 24	⇄	48	I am liked by people who are important to me in real life (e.g., friends, family members, etc.) Total Word Count: 56

Word revisions of scale items took place after each round of pre-testing. After the first round of interviews, nine items were re-worded incorporating participants' comments and feedback (Table 28). Changes were made to improve clarity and precision, length and accessibility. Items requiring rewording were reviewed in relation to the qualitative data from which they were created. This ensured that the original meaning of the item did not get lost when words were changed.

Table 28

Word Changes After the First Round of Pre-Testing of the ELSA

Item no.	Item from Version 1	Participants' feedback	Issue	Re-worded Item
5	I have people with whom I can do day-to-day activities.	Ellie (13) and Alexis (15) were unsure of what 'day-to-day activities' meant. Examples were added to address this. Tristan (13) thought the word 'whom' made the understanding more difficult.	Clarity	I have people who I can do day-to-day activities with. (For example, I have friends who I have lunch with, go to and from school/college with, study with, play videogame with, do clubs with, etc.)
10	Busy environments can make connections with other people difficult.	Emily (12) thought this item was too long.	Length	It is difficult to connect with people in busy environments.
19	I feel comfortable alone when my senses are stimulated.	Emily (12), Ellie (13) and Alexis (15) needed clarification for this item.	Clarity	Good and positive sensory stimulation makes me feel less lonely.
21	I fit in with other people.	Emily (13) described that she fits in with her friends not because she 'fits in' but because they understand her. This understanding and acceptance make her feel like she fits in.	Precision	I feel like I fit in with other people.

26	I would like to have more people to talk to everyday.	Emily (12) was unsure if this item referred to meeting and interacting with friends or to having people with whom one can talk about their feelings.	Clarity	I would like to have more friends to interact with every day.
29	Being around people is enough for me not to feel lonely.	Emily (12) questioned who were the 'people' the item referred to: known people or random people.	Clarity	Being around people I know is enough for me not to feel lonely.
35	I can make new friends independently.	Alexis (15) had difficulty understanding the meaning of this item.	Clarity	I can make new friends without the help from adults or other friends.
43	I feel alone within my community.	Alexis (15) had difficulty understanding the term 'community' and suggested using words like 'friends', 'family', 'people you see on an ever day 'basis'.	Clarity	I feel alone amongst people I know (e.g., friends, family, and other people I see on a daily basis)
52	I like being alone.	Ellie (13) said she likes being alone sometimes, but not all the time.	Precision	At times, I like being alone.

Word changes were applied to the second version of the ELSA (Appendix K), used for the second round of pre-testing. During this round, seven items were highlighted by participants as being unclear, ambiguous and lacking representation (Table 29).

Table 29

Word Changes After the Second Round of Pre-Testing of the ELSA

Item no.	**Item from Version 2**	**Participants' comments**	**Issue**	**Re-worded Item**

11	I like being with people I know.	Abi (15) suggested people I am familiar with as 'people I know' could be interpreted as people she has met before but is not familiar with.	Ambiguity	I like being with people I am familiar with.
12	I have people who are happy to listen to me.	Jayden (17) understood 'happy' in the literal sense (i.e., feeling of joy), rather than availability or willingness to listen.	Ambiguity	I have people who are there to listen to me.
17	I know how to start conversations when I am in a group of people.	Abi (15) was not sure if the 'group of people' related to familiar people or new people.	Clarity	I can start conversations with people who are new to me.
19	Good and positive sensory stimulation makes me feel less lonely.	Abi (15), Luca (12) and Simon (22) asked for examples of good and positive sensory stimulation.	Clarity	Good and positive sensory stimulation makes me feel less lonely. (e.g., cuddling a soft toy, using a weighted blanket, being in a darkened room, listening to soothing sounds, etc.)
33	I feel less lonely when I connect to fictional characters (in movies, books, series, etc.).	Simon (22) suggested the addition of 'TV shows' and 'games' in the examples.	Representation	I feel less lonely when I connect to fictional characters (in movies, books, TV shows, games, etc.)
34	I prefer online interactions.	Simon (22) needed clarification for this item	Clarity	I prefer online interaction. (e.g. texting, gaming,

		and suggested adding examples.		social media, video calling, etc.)
48	I am liked by people who are important to me in real life.	Simon (22) was unsure if the item referred to people he knows personally or idols that are important to him. He suggested examples to make the item clearer.	Clarity	I am liked by people who are important to me in real life. (e.g., friends, family members, etc.)

Rewording of items happened once again after the third and final round of pre-testing. Participants highlighted problems with clarity in four of the items (Table 30).

Table 30

Word Changes After the Third Round of Pre-Testing of the ELSA

Item no.	**Item from Version 2**	**Participants' comments**	**Issue**	**Re-worded Item**
16	I feel emotionally low.	Winter (18) needed clarification for this item. Examples were added to address the issue.	Clarity	I feel emotionally low (such as I feel down or sad, etc.)
22	I feel I am accepted as I am.	Declan (17) felt this was difficult to answer and Winter (18) asked if the item referred to 'accepted by anyone'.	Clarity	Overall, I feel I am accepted as I am.
28	Being around people I know is enough for me not to feel lonely.	Declan (17) and Ocean (19) interpreted this item differently. The item aims to elicit the experience of feeling less lonely when in	Clarity	Being in the presence of people I know makes me feel less lonely.

		the presence of familiar people.		
43	I feel alone amongst people I know. (e.g., friends, family, and other people I see daily)	Winter (18) questioned if this item referred to close friends or just people they know. The item aims to assess existential loneliness and the perception of feeling alone in the world in general.	Clarity	Overall, I feel lonely amongst people in my everyday life (e.g., in school, college, work, etc.)

The final version of the ELSA was formatted incorporating the three rounds of revisions and suggestions from the 15 autistic young people who tested the scale (Appendix M). Table 31 shows the final 52 items of the ELSA with their corresponding domains of loneliness.

Table 31

The Final 52 Items of the ELSA

No.	Item	Domain
1	I have people I can talk to about things that bother me.*	Emotional
2	I feel lonely.	Global
3	I have people who can give me emotional support.*	Emotional
4	I feel I have to hide my true self most of the time.	Existential
5	I have people I can do everyday activities with (e.g. having lunch, going to and from school/college, studying, playing videogames, going to clubs, etc.)*	Social
6	I feel different from what is expected of people my age.	Existential
7	I have enough people in real life who make me feel good about myself.*	Existential
8	I feel less lonely when I connect to fictional characters, (in movies, books, TV shows, games, etc.)	Positive

9	I have people in real life I like to be around.*	Social
10	It is difficult to connect with people in busy environments.	Experiential
11	I have important objects that help when I feel lonely.	Positive
12	I have people who are there to listen to me.*	Emotional
13	I find it difficult to be social.	Social
14	I have people who are interested in my wellbeing.*	Emotional
15	I have pets that are like friends.	Positive
16	I feel emotionally low. (e.g. I feel down, sad, etc.)	Global
17	I can start conversations with people that are new to me.*	Social
18	Good and positive sensory stimulation makes me feel less lonely (e.g., cuddling a soft toy, using a weighted blanket, being in a darkened room, listening to soothing sounds, etc.).	Positive
19	Being alone is important to me.	Positive
20	I find it difficult to get to know people out of school or college.	Social
21	I feel like I fit in with other people.*	Existential
22	Overall, I feel I am accepted as I am.*	Existential
23	I am liked by people who are important to me in real life (e.g., friends, family members, etc.)*	Emotional
24	I don't want to be around people that often.	Positive
25	I feel overwhelmed when involved in social activities.	Experiential
26	I would like to have more friends to interact with every day.	Social
27	I feel that others want my company.*	Existential
28	Being in the presence of people I know makes me feel less lonely.	Positive
29	I am happy with the number of friends I have at the moment.*	Social
30	I can be myself around people I know.*	Existential
31	I feel there are other people like me.*	Existential
32	I have people in real life who I feel comfortable with.*	Social
33	I like being on my own in safe spaces.	Positive
34	I prefer online interactions (e.g., texting, gaming, social media, video calling, etc.).	Positive

35	I can make new friends without help from adults or other friends.*	Social
36	I have people who care about me.*	Emotional
37	I feel connected to someone when we have the same interests. *	Experiential
38	I have places where I can be myself.*	Existential
39	I prefer engaging with personal interests than being with other people.	Positive
40	I feel I can communicate well with people. *	Experiential
41	I find it difficult to connect with people who are the same age as I am.	Social
42	I prefer face-to-face connections.*	Positive
43	Overall, I feel lonely amongst people in my everyday life. (e.g. in school, college, work, etc).	Existential
44	I feel misunderstood.	Experiential
45	I like being with people I am familiar with.	Positive
46	I know people in real life who understand me.*	Existential
47	I have people in real life who I feel emotionally close to.*	Emotional
48	I have people I can talk to and have a good time with.*	Social
49	I feel I am included by people who are my age.*	Existential
50	I feel judged by other people.	Existential
51	I feel happy when doing activities by myself.	Positive
52	I have deep personal connections.*	Emotional

*Reversed-scored items.

Discussion

The objective of this study was to develop a new scale suitable for assessing the experiences of loneliness for autistic young people. The emphasis of the study was on the theoretical development of the scale with particular focus on its conceptual grounding. Scale items were created from qualitative data contributed by autistic young people and from a review of relevant existing loneliness measures. The evaluation of content validity, which included the assessment of clarity, relevance and suitability of scale items, was carried out in

two phases. During the first phase a panel of five clinical and research experts evaluated the scale items. The panel was comprised of three academics, two who worked within autism research and one who worked with loneliness research and scale design. The other two were clinical psychologists who worked with autistic clients. During the second phase, scale items were evaluated by focus groups comprised of autistic people and those who support them. Assessment of content validity was followed by pre-testing of the scale by autistic young people through cognitive interviews. Qualitative and quantitative data contributed to the refinement of candidate scale items. The outcome was a loneliness scale – Experiences of Loneliness Scale for Autistic Yong People (ELSA) – with 52 items distributed into six domains of loneliness.

Scales that have been used for assessing and understanding the experiences of loneliness for autistic people have been almost exclusively based on neurotypical experiences of loneliness and do not include autistic perspectives (Grace et al., 2024; Lisboa White et al., 2024). In doing so, the use of inappropriate conceptualisations of wellbeing for autistic people can constrain how autistic experiences are represented and assessed. When compared to existing measuring instruments of loneliness, the ELSA innovates by being developed from a different conceptual starting point, informed by the qualitative accounts of autistic young people and by incorporating a proposed multidimensional structure of loneliness.

At the item level, the ELSA includes content specifically related to autistic experiences of loneliness. Items such as “I have pets that are like friends” and “Being alone is important to me” capture some of the variations in the experiences of loneliness for autistic young people that refer to a connection with the self (Moustakas, 1961), that allows for self-development, independence, creativity, imagination and insight (Nietzsche, 2009). Items such as “I feel I am accepted as I am” and “I feel like I fit in with other people” connect to

concepts of existential loneliness, which emerge from the experience of feeling different or separate from others (Bolmsjö et al., 2019; McKenna-Plumley et al., 2023; Yalom, 2020).

Existing scales that are unidimensional in measuring loneliness as a single construct capture the general experience or intensity of loneliness without differentiating between domains of loneliness. A recent adaptation in collaboration with autistic people (Love et al., 2025) focused on offering a total score of loneliness. Whilst a general score based on social and emotional loneliness might be useful for identifying individuals experiencing loneliness related to unmet social needs, it does not provide insight into ways autistic people can be supported to improve their sense of meaningful connection. Such measuring instruments seem to have more of an evaluative than a supportive function.

Despite loneliness being recognised as a multidimensional construct (van Tilburg, 2021; Korzhina et al., 2022), standardised measuring instruments used to investigate loneliness for autistic young people focus on social and emotional loneliness only (Lisboa White et al., 2024). Both these domains are centred exclusively around social relationships and were developed from 'typical' understandings of loneliness and connection. Bidimensional scales measuring loneliness as a reflection of the number and quality of social relationships, are likely to be missing items that speak for other domains of loneliness that are not related to traditional social needs, such as friendships.

The work done by Rodgers et al. (2016) exemplifies how adding subscales to an anxiety scale enhanced the understanding of the experiences of autistic children. They explained how total scores sometimes fail to provide detailed information about different profiles and how subscales can offer insights useful to guide formulation and interventions. Similarly, the proposed six domains of the ELSA may provide a basis for exploring whether different dimensions of loneliness are experienced differently by autistic young people. At

present, however, this remains a conceptual proposition rather than an established psychometric or clinical function of the ELSA. Feeling lonely can be related to one or more domains of the construct and is not reduced to the number or quality of relationships only.

The six domains of loneliness of the ELSA (Global, Social, Emotional, Experiential, Existential, and Positive loneliness), represent types of loneliness described by autistic young people. These domains consider the social aspects of being lonely, which are important for some autistic young people. However, they transcend the assessment of how adequate friendships and relationships are. Additional domains incorporate experiences of feeling misunderstood and different, reflecting structural and systemic factors that could contribute to feelings of loneliness, as well as experiences of feeling positively lonely.

Research has shown that autistic people can feel different and misunderstood in society, which makes it challenging to cultivate self-worth (Cooper et al., 2021) and wellbeing (Milton & Sims, 2016). Stigmatising discourses, such as master narratives that define autism based on deficits, can influence how young people understand themselves and build their identities (Brownlow, 2010; McLean & Syed, 2016). When 'normality' is used as a benchmark, differences are understood negatively and autistic young people can feel that they are deviating from the norm (Mesa & Hamilton, 2022a). Experiences of feeling different, internalised stigma and concealment of autistic identity, have been shown to lead to poorer mental health outcomes for autistic people (Botha & Frost, 2020). Study Two of this thesis showed that such experiences can also promote existential and experiential loneliness.

In practice, this could look like an autistic young person who is content with the number and quality of their relationships. They do not desire more friends or more social connection but still feel lonely. Their (experiential) loneliness might stem from feeling that people do not understand what it is like to be them, or for feeling too different from others

within their social contexts (existential loneliness). This example illustrates how the proposed domain may be useful to conceptually: increasing the number of social relationships would not necessarily address all forms of loneliness identified in Study Two. A more systemic approach may lead to improved outcomes.

In contrast, when autistic people can define their own identity and feel accepted for who they are, they can feel belonging and wellbeing (Milton & Sims, 2016). Taken together these findings highlight the importance of better understanding autistic experiences of loneliness and emphasise the need for fostering more inclusive communities. That could mean that interventions to address existential and experiential loneliness may have to include moving from the individual to the behaviour of communities and societies (Morrison & Smith, 2017).

As important as understanding why autistic young people feel different and misunderstood, and addressing feelings of existential and experiential loneliness, is understanding how autistic young people can achieve a sense of being ‘not lonely’. The addition of a domain of positive loneliness was particularly valuable at the conceptual development stage of the ELSA as it represented experiences that might otherwise be interpreted only as social withdrawal or isolation. Being alone and deeply engaged in personal interests might be interpreted negatively, such as being viewed as a maladaptive coping strategy for social and emotional loneliness, and as indicative of social isolation or detrimental loneliness from a neurotypical perspective (Adamo, 2004; Halsall et al., 2021). However, this understanding can be challenged and broadened to appreciate that such engagement can function as a preferred and adaptive form of self-regulation, rather than a sign of deficit. Meaningful and positive strategies used to promote connection and wellbeing by autistic young people are still little understood and can be judged negatively (Lisboa White et al., 2024; Milton & Sims, 2016). However, for some autistic young people,

engaging in personal interests and imaginary worlds can offer a pause from social challenges and promote feelings of wellbeing (Lizon et al., 2023; Long, 2025; Woods & Estes, 2023) and connection with the self. Autistic adults, for example, who engage with personal interests such as gardening, music, nature and computers have shown high levels of subjective wellbeing (Grove et al., 2018). Engaging with personal interests should not be seen as a threat to social connection but as the recognition of individual needs, that could be related to the necessity of decompression, self-regulation or simply a lower social drive. Acknowledging and validating such moments could be a way to make social activity more meaningful and pleasurable when desired.

Similarly, alternative ways of connection should also be considered and valued when trying to lessen feelings of loneliness for autistic young people. Autistic young boys have described playing video games as an important outlet for social opportunities and wellbeing (Pavlopoulou et al., 2022). Similarly, choosing to connect with fictional characters might be as beneficial as connecting with people in the real world (Webber et al., 2022). Whilst some of these personal strategies have been deemed inadequate and often stigmatised, under an ontological orientation of mutuality (Milton, 2012) they should be normalised and understood as personally meaningful. Work on other areas of autism research, such as the meaning of movements that bring improved focus, self-regulation, body connection and strengthened self-identity, have highlighted the importance of welcoming these alternative ways of being (Kapp et al., 2019; Petty & Ellis, 2024).

A potential contribution of the ELSA and its six domains of loneliness is the possibility of thinking of autistic belonging more broadly, rather than reducing it to remediating challenges faced by autistic people (Milton & Sims, 2016). Recognising that loneliness can emerge from feeling different or misunderstood and socially accepting personal strategies as valuable, can improve how autistic people see themselves and

ultimately improve their feelings of belonging. The same experiences interpreted through a neuronormative framework, in which connection is evaluated by the number and quality of relationships, risks overlooking or invalidating personally meaningful and self-regulating forms of connection.

To conclude, it is important to emphasise that autistic young people as a group should not be assumed to have a preference for fewer social relationships, lower social drive, or a desire for more social relationships. Everyone will have their own needs, which might also change depending on the phase of their lives and the context they are in. The ELSA was developed to provide a candidate framework for exploring these individual differences, but further research is needed to establish whether it can validly and reliably do so. It may have potential to support more nuanced exploration of loneliness, including personal and meaningful ways of feeling connected that have been overlooked by understandings of loneliness and connection based on 'typical' views. The six domains of loneliness represent an attempt to capture different facets of loneliness and the nuances between individuals. Establishing whether they constitute reliable and valid dimensions, and whether measuring them has practical value for autistic young people, remains an important direction for future research.

Strengths, Limitations and Future Research

One of the strengths of this project is the theoretical development of a new measuring instrument in collaboration with autistic young people and those who support them. Autistic views were incorporated into the generation of candidate items, evaluation of content validity and pre-testing of the scale. The main aim of the project was to build a measuring instrument that is representative of autistic experiences and therefore suitable for autistic young people.

The adoption of flexible and inclusive methods throughout the project aimed at having practical relevance for those taking part. Reducing individual challenges with sensory processing, or communication barriers, for example, are ways of catering for diversity. Flexible and inclusive methods promote engagement and empower individuals to take part in research that is important for them (Lewis et al., 2024; Ridout, 2017; Tyrrell & Woods, 2018). It is hoped that the project will serve as a model to other researchers interested in promoting diversity and inclusivity, contributing to the growing body of participatory research and to the ongoing paradigm shift in autism research.

Future research related to the development of this scale should include psychometric analysis, offering construct validity and reliability (e.g., Williams & Kristjanson, 2009). This will entail the administration of the survey to an adequate sample of people, which will then generate data for further development of the scale and its validation (Boateng et al., 2018). The literature on scale design is rich in recommendations on how to manage these tests and assessments, with plenty of examples to illustrate the process.

Based on the findings of the systematic review at the start of this thesis, loneliness has rarely been the sole focus of research and has commonly been investigated as a symptom or part of other areas of study, such as anxiety (White & Roberson-Nay, 2009), reputation concerns (Cage et al., 2016) and peer-victimisation (Storch et al., 2012). Once fully tested, the scale could help address this limitation by supporting more targeted investigation of autistic young people's experiences of loneliness.

Another interesting avenue of investigation would be to use the scale to identify and compare lonely and not lonely autistic individuals, rather than comparing autistic and non-autistic individuals. That could improve understanding of what makes autistic people not

lonely, helping to shape more suitable interventions for those who suffer with feelings of loneliness.

Bridging Section

The third study of this thesis was the theoretical development of a loneliness scale in collaboration with autistic young people and those who support them. The study was designed based on the foundation provided by the first two studies of this thesis.

The theoretical development of the scale was divided into four phases including item generation, assessment of content validity by experts, assessment of content validity by autistic people and those who support them and pre-testing of the scale by autistic young people. The final scale has been named Experiences of Loneliness Scale for Autistic Young People (ELSA) and contains 52 items distributed into six domains of loneliness.

The main contribution of this study was to develop a loneliness scale grounded on lived experiences. Once further development, the ELSA has the potential to be used as an evaluation tool for therapists, teachers, parents and people who support autistic young people. Responses to the scale items could serve as a conversation starter to promote a better understanding of the experiences of loneliness for autistic young people. These conversations could aid the development of suitable interventions with focus on quality of life.

Chapter 6: Overall discussion

Loneliness has been much associated with the phenomenological experience of being an autistic young person, but this presumption arose from unsuitable conceptualisations of what being lonely means from autistic perspectives. This thesis progressed from a systematic review of existing understandings of loneliness, through a qualitative exploration of autistic young people's experiences, to the ELSA. The studies provide a basis for considering how loneliness is conceptualised and understood for autistic young people. This chapter discusses the main conceptual, theoretical, methodological and practical contributions of the thesis.

Identifying a Conceptual Gap in Loneliness Literature

The first study of this thesis was a systematic review of what was already known about the experiences of loneliness for autistic young people in published academic literature. Systematic reviews can support the development of doctoral research by "demonstrating that the empirical research is novel, methodologically sound and needed" (Boland et al., 2023, p. 8). Starting the project with an analysis of the literature allowed for the identification of gaps within research about how loneliness is experienced and defined by autistic young people. The systematic review also provided an opportunity to evaluate methodological rigour in loneliness research. This evaluation focused on looking at how autistic young people have been represented and how loneliness has been measured and reported. Findings from the systematic review showed that loneliness for autistic young people had largely been studied from neurotypical perspectives. This indicated a conceptual and methodological gap that could be addressed with additional insights from autistic lived experiences.

Recognising this conceptual gap has the potential to directly impact the design of future studies. When investigating neurodivergent experiences, research designs must prioritise participatory methods, avoiding the adoption of neurotypical-standardised measures that have not had their adequacy examined. Failing to do so risks misrepresenting autistic

subjectivity by interpreting autistic experiences based on frameworks that pathologise alternative forms of being. Addressing this gap requires critical engagement with the assumption that autistic and non-autistic experiences are similar.

A Revised Definition of Loneliness That Includes Autistic Perspectives

Based on the findings of Study One, the aim of Study Two was to re-conceptualise loneliness as experienced by autistic young people, rather than assuming equivalence with 'typical' experiences. This not only allowed a more nuanced understanding of loneliness that may better represent autistic experiences but also reinforced the value of co-produced and participatory methods in advancing inclusive research.

By exploring loneliness qualitatively, using creative and flexible methods of research, Study Two challenged dominant ways of understanding loneliness to embrace experiences that have been neglected in mainstream psychology, such as alternative forms of feeling loneliness and connection. The thesis went 'back to square one'; it re-examined the construct of loneliness from autistic perspectives. This work was supported by ontological, epistemological and theoretical choices and by a commitment to the neurodiversity paradigm and participatory research methods. Loneliness was investigated as a multidimensional and context-dependent construct rather than a fixed or unidimensional state based on neurotypical experiences. To achieve this operational shift, the thesis applied Dialogical Self Theory (Hermans, 2001) to make sense of the multidimensional way in which loneliness was described by autistic young people.

This dialogical approach brought more nuance and complexity to the understanding of what might constitute 'feeling lonely' or 'feeling not lonely'. Rather than being the result of an objective appraisal of an emotion, under a dialogical perspective, the findings can be interpreted as suggesting that loneliness may emerge through relational assessments of the

many different dialogues an individual has with others and with parts of the self. In other words, under a dialogical understanding of the self, loneliness shifts from an individual deficit or from the absence of social contact to a relational disruption, a breakdown in internal and / or external dialogues that can be multiple and conflicting all at once.

Through this lens, loneliness becomes a dynamic experience, rather than a fixed or uniform state, which can vary across situations and be transient over time. Examining loneliness under this theoretical lens, also opened the possibility that loneliness may at times be reframed as a space of internal connection (positive loneliness) that may or may not involve other people.

The theoretical implication of this shift is threefold. First, it recognises other forms of connection as valid. Second, it adds other forms of feeling lonely, such as existential and experiential loneliness. Third, it moves the locus of loneliness from an individual 'deficit' or a lack of social skills to a shortfall in relational processes. To operationalise this shift, this thesis proposes the adoption of a framework that can validate differences and can capture contextual nuances, which will be discussed in more detail in the next section.

Based on the findings of Study Two, this thesis proposes a revised conceptualisation of loneliness comprising existential, experiential and positive loneliness alongside – or independently of – social and emotional loneliness. Existential loneliness has been defined as a feeling of being fundamentally separated from others or the world (Baek et al., 2023), a deep form of loneliness that is often related to feeling different from others (McKenna-Plumley et al., 2023). Experiential loneliness refers to the feeling that one's way of experiencing the world is misunderstood or dismissed by others (Stein & Solomon, 2017). Positive loneliness was described as challenging due to the absence of others, but it was also described as meaningful and wanted. Some participants described periods of being 'positive'

lonely as meaningful. These moments were described as giving them freedom from social demands and the opportunity to feel connected through diverse and personally meaningful ways.

These dimensions broadened conventional conceptualisations of loneliness which traditionally focused only on assumed unmet social needs. Instead, it aligns with existing literature that recognises loneliness as complex and multidimensional (Gedvilaitė-Kordušienė, 2017; Hadeei, 2024; Korzhina et al., 2022; Stein & Solomon, 2017) and that suggests that loneliness cannot be reduced to an objective evaluation of social relationships alone (Bolmsjö et al., 2019; McKenna-Plumley et al., 2023; Moustakas, 1961; Stein & Solomon, 2017). Loneliness can also come from feelings of inadequacy in environments or when in inter-personal relationships that are shaped by normalised social rules and expectations.

The adoption of this revised conceptualisation of loneliness, particularly the recognition of existential, experiential, and positive loneliness, has important implications for practice, specifically regarding redesign of support. Interventions that are aimed solely at increasing social interactions should not be used universally as the only way to soothe loneliness. They can overlook existential and experiential loneliness as well as ignore the validity of positive loneliness, making autistic young people feel more lonely by having to conform to normalised behaviours (Grace et al., 2022). Instead, interventions must target experiential distress and reframe existential support, by guiding communities to recognise individual needs and adopt approaches that are self-affirming and can foster feelings of acceptance and belonging.

The next section addresses how support and interventions should be designed based on this revised theoretical framework and the implications that it can have for identity and belonging.

Loneliness as Socially and Environmentally Produced: Implications for Identity and Belonging

The findings of Study Two suggest that the 'double empathy' problem (Milton, 2012) may be usefully extended from a within moment interaction to the broader social and institutional environments shaped by neuronormative expectations. Research investigating the experiences of loneliness for autistic young people has often implied that loneliness emerges from the inability of an autistic person to make and maintain social connections (Lisboa White et al., 2024). In contrast, Study Two provided evidence that, for some participants, feelings of loneliness sometimes emerge not from an individual circumstances, but from the lack of inclusivity and flexibility of environments and social contexts, that are structured around normative expectations of behaviour. From this perspective, loneliness is not solely an internal emotional state but is relational and shaped by interactions between individuals and their environments.

This understanding is supported by recent research that explored how experiences of exclusion and belonging in mainstream school settings can shape autistic adolescents' perceptions of themselves and their relationships with others (Pearson et al., 2025). Research has also identified emotional burden associated with difficulties with belonging and understanding, sensory and environmental demands, inflexible school policies and academic pressures (Kakoulidou et al., 2026; Lukito et al., 2025; Pavlopoulou et al., 2025). Autistic adults have also described multiple barriers to developing social connection, including sensory demands, lack of societal understanding of autism and an absence of shared experiences with others (Grace et al., 2025). These findings provide a contextual lens through

which loneliness, withdrawal and negative self-perception can be understood as potentially emerging through interactions between autistic young people and their social and educational environments, rather than solely as characteristics or deficits located within the individual.

Shifting the focus from the individual to the behaviour of communities might also have an impact on positive identity building, leading to improvement on feelings of existential and experiential loneliness experienced by autistic young people. McLead and Syed (2015) proposed that identity development emerges from the intersection between self and society, or personal and master narratives respectively. A master narrative is defined as a story that guides beliefs, values and behaviours and is shared culturally; a personal narrative is an individual's evolving story, which integrates their life experiences and gives them a sense of who they are (Thorne & McLean, 2003). When personal and master narratives are not aligned, the individual can experience tension or conflict, leading to feelings of inadequacy and alienation (McLead & Syed, 2015) or as identified in Study Two, existential and experiential loneliness.

Dialogical Self Theory (DST) offers a further lens to understand the relationship between social expectations, identity and loneliness. From a dialogical perspective the self is composed of multiple I-positions that develop through social relationships and engagement with social and cultural contexts (Hermans, 2001). Through these experiences, autistic young people can internalise repeated messages and expectations about appropriate social behaviour, friendship and belonging. These can contribute to self-positions, such as seeing oneself as socially inadequate, different, or even responsible for the social difficulties they see themselves having. This perspective might explain the findings in Study Two, where participants described feeling inadequate or guilty for their feelings of loneliness. From a dialogical perspective, these responses might reflect an internal conflict where personal preferences and internalised norms do not align. For example, they might feel they should be

more sociable with increased time spent with others, more socially 'competent' or better at maintaining traditional-looking friendships. In this case, loneliness becomes more than a disconnection from others, but also part of an internal dialogue between the multiple I-positions, including interpretations of who is responsible for feelings of disconnection and the reasons for it. If loneliness is felt with distress, it might be replaying negative social and cultural relationships that position the young person as feeling deficit (social loneliness), distance (emotional loneliness), misunderstanding (experiential) and difference (existential loneliness). Accumulation of these relational experiences can contribute to minority stress, as described by Botha and Frost (2020), and may be felt as a form of global loneliness.

Studies One and Two showed that dominant narratives of loneliness are limited to being satisfied or not with social relationships (Cacioppo & Patrick, 2008; Cacioppo & Hawkley, 2009; Weiss, 1973). The findings of this thesis highlighted that these dominant narratives do not acknowledge autistic experiences as part of what culturally legitimises loneliness and connection. Equally, social spaces and environments are often built around these dominant narratives, as seen in educational and clinical approaches that assume improving social competence alone can reduce social difficulties, including loneliness (Babb et al., 2021; Eccles & Qualter, 2021; Masi et al., 2011). These systems can limit the understanding of loneliness to unmet social needs, placing the promotion of social relationships and certain forms of connection as 'typical' antidotes to loneliness. Approaches like this dismiss existential and experiential loneliness which are characterised by feelings of being an outsider or being misunderstood. They also fail to recognise positive loneliness and personal strategies that can promote feelings of connection with or without involving relationships.

The findings of this thesis demonstrate that social wellbeing is not always defined by high levels of sociability. Alternative forms of connection can be recognised and validated,

thus changing the dominant narrative that currently presumes how loneliness and connection should be felt. When autistic young people feel safe to be authentic and can understand their own personal strategies as legitimate and accepted, they can create a positive sense of self (Milton & Sims, 2016). One potential implication is the value of cultivating more inclusive, supportive and empathic environments where people can be authentic. This includes accepting and normalising lower social drives and personal strategies used to promote feelings of connection and belonging.

Together these findings suggest that experiences of loneliness for autistic young people are dynamic and shaped by the interaction between identity, social relationships and broader environmental contexts. This supports the view that feelings of connection and non-belonging are not formed in isolation but are the result of the intersection of personal, social, and institutional factors. Recognising this is important for supporting the development of positive identity, which can aid a stronger sense of belonging and in turn help to reduce experiences of loneliness (Stark et al., 2025). This includes fostering more accepting and inclusive environments that move beyond individual change (Milton, 2012) and represent 'community-based' interventions. A neurodiversity-informed perspective raises the possibility of shifting the focus from how the individual can be 'fixed' to fit the norm, towards adapting the environment to accommodate alternative forms of being. This includes accepting and validating personal strategies that promote connection and wellbeing and aligns with wider neurodiversity-informed literature that challenges normative assumptions (Chapman, 2021; Walker, 2021).

In summary, autistic young people navigate powerful, dominant master narratives that dictate how friendships, connections, and social success 'should look'. The theoretical implication here is that the experiences of loneliness for autistic young people are deeply intertwined with identity development and the psychological toll of internalising these

deficit-based master narratives. These findings have implications for practice as they offer guidance for parents, professionals and clinicians working with autistic young people to recognise and validate diverse preferences for connection, positive loneliness and relational authenticity. This implies incorporating identity-affirming frameworks, rather than designing support based on neurotypical social norms. Support for autistic young people could include opportunities to question or negotiate harmful master narratives, helping them to build an authentic sense of belonging based on their own parameters. The findings can also prompt reflection on how current social environments and systemic structures could be contributing to the experiences of loneliness described by autistic young people.

Positive Loneliness and Autistic Led Strategies for Connection

Study Two generated accounts that described loneliness as an ambivalent emotion. Autistic young people said that despite their ongoing need to belong, they enjoyed being free from social demands and felt that the time spent in the absence of others could be productive and positive. This was defined as positive loneliness, a concept discussed by philosophers (Kierkegaard,1992; Mosé, 2018; Nietzsche, 2009) and humanistic psychologists (Moustakas, 1961) as a necessary and transformative experience which can lead to self-fulfilment and self-actualisation.

When experiencing positive loneliness, autistic young people described alternative forms of connection that included engaging with pets, with nature or with fictional characters. They also mentioned a connection to the self when busy with personal interests, such as playing musical instruments, scrapbooking, sewing, reading or being immersed in imaginary worlds. In prior research, alternative forms of connection were also reported by autistic adults who described social media groups as providing a sense of inclusion and time spent with pets described as meaningful and helping to lessen loneliness (Grace et al., 2025). Some of these experiences, particularly connections with fictional characters, can be considered in relation

to the construct of ‘parasocial relationships’. Parasocial relationships have been defined as non-reciprocal socio-emotional relationships with media figures and have been conceptualised as an extension of social relationships (Tukachinsky et al., 2020). This construct would require further critical interpretation in the context of the findings of this thesis; assumptions that non-reciprocated social relationships do not substitute other relationships and assumed limited personal importance should be approached through a non-pathologising and neurodiversity affirming researcher lens. However, when these individual strategies are situated in broader social contexts, despite being reported as soothing and beneficial, they can be interpreted as pathological and maladaptive (Adamo, 2004; Halsall et al., 2021).

This tension between subjective wellbeing versus pathologisation can also be seen in research in the field of imagination and unusual sensory experiences. Somer et al. (2021) researched reality shifting, whilst Palmer-Cooper et al. (2022) explored experiences of tulpamancy (the creation of invisible companion entities) and Autonomous Sensory Meridian Response (having physical sensations when listening to or watching specific stimuli). These experiences have also been subjected to stereotyped and pathological interpretations (Alderson-Day, 2026). However, new paradigms suggest understanding these phenomena as being experienced somewhere between imagination and reality, without necessarily implying distress or intrusion (Palmer-Cooper, 2026). In this view, the focus in not on determining whether an experience is ‘real’ or ‘imagined’, but on how it is subjectively experienced and integrated into a person’s sense of self and lived experience.

In contrast, approaching these phenomena from a pathological perspective may divert attention from their potential for promoting wellbeing (Alderson-Day, 2026). Similarly, when judged against dominant social norms, and assessed from a pathological perspective, positive loneliness and autistic led strategies for connection may be suppressed by the individual,

rather than recognised as meaningful. These dynamics reflect how dominant narratives of ‘normality’ and ‘pathology’ inform whether experiences are interpreted as valid strategies or behaviours that should be ‘fixed’ or avoided. A more nuanced understanding may help identify what works for whom, as Milton (2014b) suggested when discussing what kind of interventions are appropriate for autistic people.

This argument is further supported by autism research highlighting the importance of recognising and validating alternative forms of self-regulation and adaptive mechanisms, such as stimming (Kapp et al., 2019), which despite their reported benefits, are often suppressed due to social pressures (Charlton et al., 2021). Similarly, research on repetitive behaviours, rituals and routines found that autistic people who can move “freely, expressively and sometimes repetitively” (p. 3015) described benefits to sensory regulation, general wellbeing and contribution to positive identity building (Petty & Ellis, 2024). When autistic people perform their rituals and routines, there is a subjective sense of wellbeing (Petty et al., 2025). As demonstrated by these findings, approaches that seek to understand subjectiveness have the potential to turn autistic led strategies into tools for connection**.**

The conceptualisation of positive loneliness developed in this thesis should not be interpreted as suggesting that autistic people generally prefer to be alone, that loneliness is inherently beneficial, or that painful experiences of loneliness should be reframed as positive. Rather, it highlights the importance of distinguishing between being alone, wanting to be alone, and experiencing loneliness. Social Motivation Theory (Chevallier et al., 2012) provides one possible theoretical framework for understanding why social interaction may not always be experienced as rewarding or motivating. Positive loneliness therefore refers to the possibility that experiences of being alone may sometimes be valued and meaningful, rather than to a characteristic preference for loneliness among autistic people. It is acknowledged that ‘positive loneliness’ is an imperfect term for capturing these complex and

context-dependent experiences, and further research may help to refine the terminology and conceptualisation. The term holds tensions that exist between assuming that aloneness is inevitable for autistic people, that loneliness is a positive experience only in its reprieve from lesser preferred demands, and that loneliness can be a positive experience in its own right with rich and personally meaningful rewards. The term is chosen to welcome further critical dialogue.

A key finding of this thesis is the recognition and definition of ‘positive loneliness’, a domain that has been extensively discussed by philosophers and humanistic psychologists. They talked about the pain and despair associated with loneliness but also acknowledged it as a creative and productive force that allows meaningful awareness of the self and engagement with deeper aspects of life (Kierkegaard, 1992; Moustakas, 1961; Nietzsche, 2009). In dominant narratives, loneliness has often been understood as a negative state. If someone chooses to be alone and feels positive about it, that is called ‘solitude’ (Tillich, 1963). Positive loneliness is different. It has been described by autistic young people as a challenging but meaningful state, that offers rest from social demands and the possibility to engage with alternative modes of connection.

A theoretical implication of this concept is a loneliness model that separates the absence of others from emotional distress. Positive loneliness, may in some contexts, be experienced as an adaptive or regulating state rather than an experience requiring intervention. For research, this implies that future scales measuring loneliness could consider including items that capture the positive, restorative utility of being positively lonely. One implication for practice is the value of including autistic perspectives when interventions are designed, creating opportunities for autistic young people’s personal strategies to be recognised and considered in intervention design, rather than being the target of interventions that aim to "fix" their positive loneliness.

The ELSA and Implications for Practice

Study Three extended the findings of the previous two studies by focusing on the theoretical development of the Experiences of Loneliness Scale for Autistic Young People (ELSA). The ELSA is a 52-item scale that assesses six domains of loneliness (global, social, emotional, experiential, existential and positive loneliness). It was developed in collaboration with autistic young people and those who support them, reflecting the participatory ethos underpinning the thesis.

The development of new measurement tools is often recognised by researchers as a resource-intensive process, that requires substantial investments of time, expertise and funding (Streiner et al., 2015). General guidance recommends evaluating, and when appropriate, adapting existing instruments before developing new ones. A key conclusion of this thesis is that existing measures of loneliness may not adequately capture the experiences of autistic young people. This was informed by both conceptual and empirical limitations identified in Studies One and Two. The systematic review identified that measuring instruments that have consistently been used to investigate loneliness for autistic young people do not include autistic perspectives, indicating a lack of suitable loneliness scales. Study Two showed that loneliness is described by autistic young people as being multidimensional, extending beyond the social and emotional domains to include existential, experiential and positive loneliness – domains that have not yet been incorporated to loneliness measures. These findings indicated that adaptation of existing measuring tools would be insufficient.

Adaptations become particularly limited when considering how the construct of loneliness has been defined in existing measures. As highlighted by Boateng et al. (2018), careful attention must be given to how the domain of interest is conceptualised during scale development. Consequently, adaptations of measures for autistic people risk bypassing this

critical step by starting with a priori assumptions of the construct being measured. If the construct has been based on neurotypical views, it will possibly exclude relevant autistic experiences. Evidence from related work further supports this critique. For example, Nicolaidis et al. (2019) found that autistic partners were not satisfied with an adapted measure of healthcare self-efficacy, as it did not adequately addressed issues that they identified as most important for autistic adults. This evaluation highlights the limitations of adaptation approaches when foundational constructs remain unchanged.

In the context of loneliness, these assumptions are largely informed by neurotypical experiences of social and emotional loneliness, and do not include autistic views. Consequently, even collaborative adaptations will focus on validating existing items related to these two domains of loneliness, rather than representing the broader, multidimensional nature of loneliness as experienced and described by autistic young people. Building on this rationale, it was concluded that adapting an existing measure would be insufficient to address the lack of suitable scales of loneliness for autistic young people and that a new measure should be developed collaboratively.

Study Three therefore involved the co-development of a new scale based on the revised conceptualisation of loneliness generated in Study Two. In addition to addressing conceptual considerations of loneliness, the practical aspects of the ELSA were also developed in consultation with autistic young people. Following guidance on how to incorporate autistic perspectives into the development of measuring instruments (Nicolaidis et al., 2019), autistic young people contributed to the wording of items, suggesting changes to address complexity and ambiguity. They also informed the response format, including the range and style of options. This process aligned with participatory approaches that aim to reduce epistemic imbalance by embedding autistic perspectives in all stages of measurement development. The Methods section in Chapter Five describes this collaborative process of

knowledge production, offering detail that has often been omitted from prior accounts of measurement development. The main methodological contribution of Study Three is not just the scale itself, but the demonstration that participatory conceptualisation is necessary for valid measurements. This will be further discussed in the next section.

The ELSA does not presume how loneliness is experienced. It is not another questionnaire assessing social and emotional loneliness. The ELSA was grounded in autistic young people's accounts, resulting in a measure that reflects lived experiences and can enable a more nuanced understanding of the experiences of loneliness for autistic young people. However, although the involvement of autistic young people was an important step on the development of this measure, it does not capture the breadth and heterogeneity of loneliness experiences across autistic young people. In addition, at this stage, the ELSA should be understood as a measure in development rather than as a validated instrument. Further research is needed to evaluate the psychometric properties of the ELSA in larger and more diverse samples of autistic young people. This would enable researchers to establish its reliability, and utility in practice.

The practical application of the ELSA should also be further evaluated. The findings of this thesis suggest that a measure based on a multidimensional conceptualisation of loneliness may have potential to support a more nuanced understanding of autistic young people's experiences. Further research could investigate whether the ELSA might be useful as a prompt for conversations about loneliness, connection and individual needs in educational, therapeutic, family and support contexts. If accepted, the ELSA could facilitate meaningful conversations about loneliness and improve understanding of needs with a focus on quality of life. This may also facilitate multidisciplinary practice, including psychological formulation of need (British Psychological Society, 2011) by providing healthcare

professionals with a basis for understanding and discussing experiences of loneliness with autistic young people.

Besides having potential to support a better understanding of the experiences of loneliness, the ELSA could have implications for intervention and support. Consistent with Milton's (2014b) emphasis on 'what works', support should be responsive to individual needs rather than based on general assumptions of deficit or disorder. In line with this argument, Hull et al. (2025) found that some autistic adults want support with social skills, but others feel that this sort of intervention is not necessary. Participants suggested that when recommended and desired, interventions should be personalised and accessible. In the context of loneliness, this includes recognising how loneliness is multidimensional and contextual. The ELSA may provide a route to understanding and valuing this complexity, including recognising that not all experiences of aloneness are negative. If future research establishes the validity and practical utility of the ELSA, its multidimensional structure could potentially provide a basis for exploring whether different experiences of loneliness are associated with different support needs. For example, interventions to improve social connections and expand social networks will be valuable when individuals feel social and/or emotionally lonely. When feeling existentially and experientially lonely, it might be helpful to assess the environments and communities involved and possible accommodations that might lead to feelings of belonging. Similarly, positive loneliness should be explored as a possible path to adopting personal and meaningful strategies that promote feelings of connection and belonging. By capturing autistic experiences of loneliness and legitimising autistic led strategies of connection, the ELSA could potentially aid the development of support that aims to improve autistic people's lives, with health and wellbeing as their primary goals (Pukki et al., 2022).

The methodological implication of the ELSA is that it provides an example of how psychometric tools can be developed alongside the community, showing that participatory research can meet rigorous psychometric standards without compromising autistic voices.

Methodological Contributions and Implications for Future Research

This thesis was anchored in the neurodiversity paradigm and situated within a critical realist ontological orientation, which assumes that reality exists but not without context and perspective (Braun & Clarke, 2022b; Kourti, 2021). This critical realist ontological stance was paired with an epistemological commitment to participatory research, which emphasises the importance of including lived experience in generating valid knowledge (Fletcher-Watson et al., 2019; Milton, 2014a). From this perspective, instead of being shaped by power relations that position autistic people as objects of study, research is thought to rebalance these dynamics, by recognising lived experience in the production of knowledge (Milton, 2012; Pellicano et al., 2014). Addressing this imbalance requires methodological approaches that are flexible, inclusive and responsive (Lewis et al., 2024), such as creative methods and inclusive modes of participation adopted in Studies Two and Three.

In Study Two, autistic young adults were consulted about the best methods to engage autistic young people in research. This participatory step ensured that the research design reflected autistic preferences for engagement and accessibility. The panel of autistic consultants suggested offering participants choices of flexible and creative methods of data collection together with varying modes of participation. These decisions were supported by practice-based guidelines that emphasise the importance of offering multiple modes of participation and of adopting methods to accommodate autistic people's preferences for inclusive autism research (Nicolaidis et al., 2019; Pickard et al., 2022). Such approaches aim to reduce barriers to participation and is a step towards empowering epistemic agency (Catala

et al., 2021; Nešić, 2023), by enabling autistic people to meaningfully shape knowledge production.

Besides being inclusive, Study Two had an exploratory design, which is usually used to investigate areas where knowledge is limited (Stebbins et al., 2008). Given that loneliness had rarely been defined from the perspective of autistic young people, an exploratory design was considered appropriate. Such designs are also recommended when there is reason to believe that the phenomenon has elements that have not yet been considered (Stebbins et al., 2008). In practice, the exploratory strategy was adopted in the form of open-ended questions, supporting a holistic understanding of the subject being investigated (Albudaiwi, 2017). This approach paired with creative and flexible methods, allowed participants to share personal, unique, and sometimes unexpected perspectives, without imposing a priori assumptions. Similarly, by inviting participants to contribute to the interpretation of findings through participatory data analysis, the aim was to avoid pre-established assumptions and ensure that knowledge production was guided by autistic perspectives. As a result, the study generated a nuanced and participant-informed understanding of loneliness, showing that autistic experiences sometimes do not align with pre-existing conceptualisations.

The use of creative and flexible methods in this thesis prompted reflection on how the methods are not only a means of accessing participants' experiences, but their influence on the experiences that become available as data. This is important when investigating experiences that can be difficult to articulate, such as loneliness and connection. Although Study Two offered participants a range of ways to communicate, future research could consider how to give participants greater control over the ways in which their experiences are expressed. For example, rather than choosing from a predefined menu of creative activities, participants could be invited to decide how they would like to communicate their experiences, rather through one method or a combination of different methods. This is

particularly relevant to epistemic justice. Providing greater control over modes of communication and expression may therefore extend the participatory principles adopted in this thesis and further redistribute control over knowledge production. To do this, researchers could refer to recent research with neurodivergent young people that have strived to make research processes accessible and predictable (Kakoulidou et al., 2024; Pavlopoulou, 2020; Pavlopoulou et al., 2026).

Study Three was also designed to be collaborative and consideration was given to creating inclusive environments (Gatfield et al., 2018) by adopting flexible methods of participation. Autistic young people and their communities co-produced the ELSA by evaluating content validity and by re-wording items. This was followed by pre-testing of the survey, where autistic young people gave feedback on each item, modified the response range and options, and suggested changes to the layout of the survey. The collaborative approach was intended to increase the extent to which the ELSA reflected autistic experiences and preferences. In addition, it includes content specifically related to autistic experiences of loneliness.

A key methodological contribution of this thesis was the development of an inclusive research framework that combined exploratory inquiry with participatory principles. The thesis provides examples of ways in which autism research can move beyond consultation towards forms of shared knowledge production. This can be achieved by allowing participants to choose how they want to engage and by involving them in participatory data analysis and co-production of resources. At the same time, the methodological reflection above suggests that participation should not be understood only in terms of whether participants are included in particular research activities. The degree of control participants have over how those activities are designed and how their knowledge is expressed is also important. The model used in this thesis contributes to the growing field of participatory

research and illustrates how methodological flexibility can generate rich and relevant accounts of autistic experiences. By including autistic voice to research, the thesis moved autistic young people from being participants to being contributors to theory. The findings reshape the understanding of loneliness, the way it is assessed and investigated for autistic young people.

Conclusion

To conclude, this thesis developed from a systematic review of existing literature, into a qualitative exploration of the experiences of loneliness for autistic young people. The findings of the first two studies grounded the theoretical development of the ELSA; a loneliness scale created in collaboration with autistic young people and those who support them. Across all stages, there were ongoing and significant efforts to make this thesis inclusive and participatory. Creative and flexible methods were adopted to include autistic perspectives in the validation of research questions, study design, data analysis, and development of the scale. Researchers can refer to this methodology to inform design and knowledge production that is grounded in lived experience and therefore relevant and meaningful to autistic people.

Aligned with the ontological and epistemological principles stated at the start, the findings collectively offer a revised conceptualisation of loneliness that incorporates autistic perspectives. The ELSA represents a synthesis of these findings and provides a measure that reflects the multidimensional conceptualisations identified in this thesis. Further psychometric validation is required to establish whether the ELSA can reliably and validly support the assessment and understanding of loneliness for autistic young people.

Chapter 7: Reflexivity

Reflexivity in qualitative research involves interrogating the influence researchers' practices have on the research process (Braun & Clarke, 2022b). It consists of identifying and taking responsibility for how researchers' positionality can influence knowledge production (Berger, 2015). Reflexivity should also consider how representation may shape new understandings and findings generated by research, community participation, and the value that the research holds for those it seeks to represent (Thompson-Hodgetts, 2023). Consistent and disciplined engagement in reflexivity is also considered a means of demonstrating rigour, quality and transparency in qualitative research (Dodgson, 2019). During this thesis, reflexive practices were applied to consider relationships with participants (personal reflexivity), to interrogate methodological choices (functional reflexivity) and to reflect on epistemological and theoretical positioning (disciplinary reflexivity) (Braun & Clarke, 2022b; Wilkinson, 1988), ensuring alignment between theory and practice.

The following sections will approach each of these reflexive practices in turn. First-person writing was adopted to make the reflexive nature of this chapter explicit and to acknowledge the researcher's voice in the research process and knowledge production.

Personal Reflexivity

As part of the epistemological position adopted for this project, I acknowledge my own epistemic limitations in producing knowledge for autistic young people, as a non-autistic researcher. In this section, I reflect on my professional background in education and my social identity in relation to the research project and how my biases and pre-assumptions might have influenced the research process.

I do not identify as autistic. In fact, my very understanding of positionality evolved with time and experience. I started my professional career as a primary school teacher and

held varying teaching roles in independent and state schools. Throughout the years I worked with many neurodivergent students and understood the importance of accommodating individual needs. Examples include using support materials during lessons such as visual prompts, written cards to help with communication, different time frames for completing work, offering alternative methods of recording answers and support for managing schedules (Xu et al., 2025). The promotion of enabling environments was also discussed amongst staff and incorporated ear defenders, comfort breaks, quiet rooms for decompression and sensory toys. Despite the day-to-day challenges of teaching, such as the lack of resources, overwhelming workload, feeling undervalued by society and lacking autonomy (Solvason et al., 2026), my practice was guided by compassion (Hamilton & Petty, 2023). This meant listening attentively, empathising and being proactive in trying to remove obstacles to students (West & Chowla, 2017), including adapting communication, offering flexibility where possible, and responding to individual needs to support meaningful engagement in learning.

Currently unpopular, ‘differentiation’ was considered an important practice in education (Deunk et al., 2018). Teachers were expected to identify and cater for students’ individual needs, making sure that every child made suitable progress during the academic year (Taylor, 2017). ‘Accommodating’ or ‘adjusting’ often meant preparing several versions of the same task, simplifying content, lowering expectations for some students, and offering interventions, a type of bolt-on provision which is delivered outside core teaching. At the time, the idea of a Universal Design for Learning (CAST, 2021), where inclusive classrooms anticipate learner diversity from the outset rather than relying on remedial provision (Rao et al., 2023) was unheard of. However, ‘inclusion’ was becoming more prominent as a marker of good practice in British schools and as part of equality and anti-discrimination policies such as the Special Educational Needs and Disability Code of Practice (Department for

Education and Department of Health, 2015) and the Equality Act (2010). These provided guidance on how to support pupils with special educational needs, emphasising the need for adjustments and tailored support, as well as strengthening the legal basis for inclusive education. 'Inclusion' meant making sure all students could access the curriculum, were socially integrated in school and had support provision. I saw changes in education day-to-day as more students with varied needs were admitted to schools, liaising with external agencies increased, assessments were reformulated and teachers were encouraged to adopt more responsive and flexible strategies of classroom management.

Despite the advances in support for inclusion of children with neurodevelopmental, psychiatric and physical diagnoses, the dominant approach to neurodivergences in schools was based on the medical model of disability, where autism was understood as a disorder and differences were seen as deficits (House of Commons Education and Skills Committee, 2006). Teachers were expected to close the gap between autistic and non-autistic children, by helping autistic students to 'overcome their deficits'. Progress was measured against benchmarks defined by standardised measures such as the Phonics Screening Test (Department for Education, 2012), Early Years Foundation Stage Profile (EYFSP) (Department for Education, 2025) and Key Stage 1 Statutory Assessment Test (SATs) (Standards and Testing Agency, n.d.), usually based on neurotypical behaviours and milestones. At the time, my view was that I had to support every student to achieve these standardised measures, despite challenges or individual needs. I did not think critically about the actual measures and how they had been formulated based on 'typical' development and behaviours. I also lacked awareness of my alignment with a medical model of disability and a positivist orientation.

In addition, the schools where I worked were characterised by a traditional power imbalance and asymmetrical relationships between pupils and teachers, typical of

institutionalised roles (Ladkin, 2017). Within this power dynamic, teachers tend to be held accountable for pupils' learning (Robinson & Taylor, 2013), keeping control of classroom management, knowledge and assessment, and influencing social norms. Social norms for an autistic young person might mean adapting communication style, overcoming other people's misconceptions about autism, feeling pressure to look or act 'typical' and managing sensory distractions (Milton, 2012). This, in turn, can impact negatively on the ability of students to voice their views and concerns that could contradict teachers' superiority (Ladkin, 2017; Mullally et al., 2024).

When I first applied for this PhD, I had not yet reflected on where conceptualisations of being autistic came from, nor on how being non-autistic could shape the production and interpretation of knowledge. My mindset was heavily influenced by the power conferred to me as a teacher and by normative power imbalances, where the dominant systems tend to reflect and favour the experiences of those who are privileged and fit in (Saunders & Wong, 2020). I thought my experience as a teacher and the 'success' I had achieved with neurodivergent young people under a medical understanding of autism, would be enough to produce meaningful outcomes. I can also see the genuine care I had for my students and how I supported them the best way I could with what I knew at the time. I remember, for example, one student who developed confidence and subject competence in Maths by being consistently provided with enough time to process questions and work out solutions. At the time, I was offering this support without judgement or pressure for them to conform to a more 'typical' pace of working. This also meant that my expectations were not lowered, but the support put in place enabled them to develop their abilities and achieve the same academic standards as their peers. I look back at this as an example of success. Yet, there is a paradox in how I understood that success. Although the driving force behind my approach was a firm belief that I was helping students reach neurotypical milestones and standards, the

strategies that proved most effective were often those that removed barriers to participation and enabled them to engage on their own terms. Looking back, I can see that I was removing barriers to participation and learning, despite not yet having the theoretical language of the social model of disability or a neurodiversity-affirming framework to understand this practice.

With the beginning of the PhD, my views of autism and neurodevelopment started to change, first influenced by the ontological and epistemological positioning of my supervisors, and from the research culture within the department of Psychology, at York St. John University (YSJ). As I started my research, I learned more about the neurodiversity paradigm and social model of disability. I started to understand the weight and importance of representation in research when pursuing meaningful outcomes (Chown et al., 2017; Fletcher-Watson et al., 2019; Pellicano et al., 2014). This learning process started with me being part of an inclusive research community at YSJ guided by principles of social justice. The learning continued with an immersion in the world of autism research by accessing seminal papers (e.g. Milton, 2012; Sinclair, 1999), autobiographies and memoirs written by neurodivergent authors (e.g., Cook, 2018; Grandin, 2009; Prahlad, 2017; Price, 2022), taking part in research group discussions, talking to colleagues, going to conferences, but most of all, by getting closer to the autistic community.

Milton (2012) coined the ‘double empathy problem’, explaining that the difficulties in communication and interaction between autistic and non-autistic people are faced by both sides, but can be reduced through mutual cultural understanding. Being with autistic people throughout this thesis gave me insight into autistic culture and lived experience, helping me to reconsider my own beliefs and understanding of autism. In particular, I noticed that when differences in communication and pace are acknowledged, both sides of the interaction might have to adjust. For one semi-structured interview during Study Two I had to calibrate my

expectations of having instant responses as one participant took his time to process my questions and to elaborate an answer based on his experiences. Another participant who was in Study Two chose to engage with data collection through writing, which for me was a new experience. I spoke and they wrote. After their participation I reflected on the impact of having flexible modes of engagement as described in Chapter Four. For them, I hope it meant they felt included and valued, and for me it meant widening my world view and the privilege of learning from their experience in a way that I might otherwise never have accessed. This experience also highlighted the importance of challenging assumptions about what constitutes 'valid' communication and recognising that different modes of expression are not lesser alternatives but equally legitimate ways of sharing knowledge and experience. These interactions also shaped the direction of the research and my positioning as a researcher, influencing both my intentions and the way I came to understand the purpose of the work.

I had many fulfilling moments and fruitful interactions with autistic young people, family members, teachers and mentors during the PhD. The more I interacted with them, the more I understood the need to be inclusive and flexible. By this I mean that I gradually understood that knowledge is multiple (McArdle, 2022), and that to access it I would need to diversify methods and foster engagement by focusing on diverse strengths and interests of autistic young people (Lewis et al., 2024). This motivated the application for grants, the inclusion of participatory data analysis in Study Two and the collaborative design in Study Three.

Although my understanding of autism and inclusion has changed throughout the PhD, as a non-autistic researcher, I recognise that there are limits to what I can understand about what being autistic is or feels like, and that my interpretations may still be shaped by neurotypical norms. The thesis has helped me to understand that inclusive practice is not simply about adapting methods, but about continually questioning the process of knowledge

production. This includes working collaboratively and centring lived experience as an essential source of knowledge. I hope to carry this awareness in my future teaching and research practice by remaining critically attentive to how my own approaches or institutional norms may reproduce exclusion.

Disciplinary Reflexivity

In this section, I reflect on the philosophical underpinnings of my professional practice and academic trajectory and how they have influenced this thesis. Through this process of reflection, I recognised a paradox. Academically, I have always identified with qualitative methods of research. I worked with narrative analysis (Riessman, 2008), discourse analysis (Burr, 2015), interpretative phenomenological analysis (Smith et al., 2009) and more recently reflexive thematic analysis (Braun & Clarke, 2022b). Despite differences between these approaches, they all sit within interpretive qualitative inquiry. The focus on meaning, experience and social context is aimed at understanding how people make sense of their worlds, challenging positivist traditions that seek to measure and quantify variables. On the other hand, my professional training in Education led to a deficit-based understanding of autism and a focus on 'fixing' behaviours or helping autistic young people reach neurotypical milestones and standards.

I believe this initial mismatch between theory and practice mirrored the usual gap between knowledge production and policy (Whitty, 2015). Whilst I personally identified with theoretical investigations that centred the individual and their experiences, I was still working in a system that valued quantifiable variables and standardised measures for all students. When I started my PhD, my research project became my 'practice', and I had to find ways to coherently align philosophical assumptions and methodological approaches. I was rapidly convinced by ontological discussions in the field of autism research that pushed for a shift in paradigm (Pellicano & den Houting, 2022; Sonuga-Barke, 2023), as these aligned with many

of the philosophical assumptions that underpinned the qualitative methods I was familiar with. I agreed with the idea of centring autistic voices and working together with autistic people to produce meaningful outcomes. However, I was out of my depth in practical terms. The toolbox I had available from my professional practice as a teacher was not suited to translate this ontological positioning. It took time and work to develop the skills, the language and the strategies that would become more suited to the project and more aligned with the neurodiversity paradigm. This process is detailed below in the section about functional reflexivity.

Functional Reflexivity

In this section, I reflect on the learning, unlearning, and practical changes that were necessary to bring my research practice into closer alignment with the theoretical and philosophical foundations that informed this thesis.

The first stop on my learning journey was adjusting the use of language. The initial documents I wrote referred to autistic young people as a 'population', 'adolescents with ASD', or 'adolescents with Autism'. I also wrote about 'loneliness in' as opposed to 'experiences of loneliness for' autistic people. These terms usually reflect an ontological positioning aligned with the medical model of disability rather than the non-deficit and non-ableist approach I was interested in (Kapp, 2020; Kenny et al., 2016; Pellicano & den Houting, 2022). This shift happened gradually through reading, supervisory feedback, conversations, observations and immersion in autistic culture.

The next significant learning point was to include autistic voice as a necessary part of the research process (Botha & Cage, 2022; Milton, 2014a). Despite the budget and time constraints typical of PhD programmes, I felt this was essential to produce valid and meaningful outcomes. Including consultation and collaboration with autistic people and those

who support them was also formative. As a researcher, I engaged with lived experience from a novel point of view. Rather than managing behaviours or being responsible for finding strategies to 'help' autistic young people as I did in my role as a teacher, I adopted a more curious and open stance as a researcher. I was there to explore autistic experiences, to learn from their narratives and to shape the culture within which the research was taking place. These experiences of interacting with autistic young people, their parents, teachers and mentors, helped me to get familiarised with differences in communication. They helped me to adjust my own social expectations, contributing to high-quality interactions and to my personal education on epistemic justice. This influenced the choice of methods and incorporation of participatory data analysis in Study Two and the collaborative work carried out in Study Three. As an example, I incorporated flexibility into the research design so that sessions could be paused or reshaped in response to participants' preferences and comfort. In doing so, I came to appreciate that research and knowledge production can be messy and are often relational and unpredictable processes. This challenged my previous assumptions about academic inquiry as something that should be tightly controlled and linear. Instead, I learned that rigour does not require rigidity; rather, rigorous research can emerge through responsiveness, reflexivity, and a willingness to adapt (Lewis et al., 2024).

When I started integrating participatory research into the thesis, I was reminded of a revolutionary mind. Although Paulo Freire's work was developed in the field of adult education, it offered relevant theoretical and philosophical support for the use of participatory methods. Freire's seminal work *Pedagogia do Oprimido* (1967) (published in English, in 1970, with the title Pedagogy of the Oppressed), talks about power imbalances and the importance of dialogue in the generation of knowledge. Freire explains that dialogue is based on four basic principles: humility, where no one has a monopoly of knowledge; faith in people and their capacity to transform reality; hope, not as a naive optimism, but as a

commitment to the possibility of transformation through collective action; and critical thinking, allowing people to challenge oppression and reimagine the world. The four principles described by Freire can be valuable for autism research and as part of my reflexive journey, I could identify parallels between them and those that inform participatory research.

The principle of humility has been previously discussed as the importance of understanding autistic people as experts of their own experiences (Gillespie-Lynch et al., 2017) and the need for dialogical partnerships and meaningful involvement of neurodivergent perspectives in the production of knowledge (Shaw et al., 2025). As the researcher, I had to let go of the monopoly of knowledge. If I was back in the classroom, I would have probably found giving up the monopoly of knowledge quite challenging, as I had many years working within a different paradigm. However, this was my first time conducting research with participants and maybe for this reason, I found it quite reassuring to have people with lived experience adding to the research process. An example of this was changing the scale response format from a design I had based on literature to a design suggested by participants. Their input made the change feel meaningful, as it improved accessibility and clarity from their point of view.

The principle of faith discussed by Freire has a parallel with the trust in autistic people to participate in shaping social transformation, rather than treating autistic people as passive subjects in research (Fletcher-Watson et al., 2019). During repeated visits to participants at their school or college, I adopted an open and flexible stance, respecting their space and time. Sometimes, I would spend extended periods of time on site and without any young person feeling ready to talk to me, due to overwhelm or a preference to participate at a later point. It felt frustrating at times, but on reflection, it was all part of building rapport and trust. Recognising that participation might require multiple encounters and a degree of familiarity with the person conducting it, was all part of my learning process. Adapting my

rhythm and expectations, being understanding and flexible, brought me closer to the community, thus helping to build trust. At the same time, when invitations to contribute to the dissemination of findings were declined, the practical challenges of ongoing engagement became clearer. This reflected the need to remain attentive to participants' capacities, interests and competing demands. It also pointed to the importance of flexibility – offering a wider range of modes of contribution may have facilitated greater involvement.

The principle of hope can be identified in strategies to promote inclusivity and to overcome systemic barriers for autistic people. This shows commitment to transformation and the belief that better outcomes are achieved through enabled collective action. The principle of critical thinking involves researchers being reflexive about research agendas, whose voices are being amplified, and how findings are being interpreted and disseminated. During the four years conducting this research project, I had many positive and reassuring comments from autistic people, clinicians, parents, mentors, teachers and school staff. Many people commented on the relevance of the topic for autistic young people and praised the creative and flexible methods that were being used. However, the most touching comments were those that expressed hope. Many were hopeful that the research would start a conversation about loneliness and more importantly, that this conversation included and was being guided by autistic young people. When people are empowered, they can challenge dominant perspectives and shape new realities.

I am also hopeful after being through this experience of working with autistic young people. Being invited back by schools and colleges to give talks to students and parents, contribute to an impact report, and even serve as a judge in an art competition during neurodiversity week made me feel accepted by these communities. Being an active member of the community by taking part in such activities is often a less visible form of engagement, nonetheless, it is an important aspect of building partnerships for participatory research (Reed

et al., 2014). Although I am not autistic, I have felt welcome, and these relationships have come to feel like genuine partnerships – ones I hope to continue to nurture and learn more from.

Final Thoughts

Learning and adopting participatory methods helped me to challenge my normative idea of knowledge production (May, 2024). Today, thanks to autistic advocates, to valuable conversations and to my involvement with the autistic community I have a better understanding of the relevance and impact of identity and positionality in the production of knowledge (Wilson et al., 2022). I have also learned throughout this PhD that reflexivity is ongoing and situated rather than a fixed or completed process.

I recognise that, although centring autistic voices and adopting participatory methods was valuable to the knowledge production of this thesis, these practices were still embedded within institutional structures that continue to privilege researcher-led interpretations, academic authorship and definitions of rigour. Whilst participatory engagement brought opportunities for shared decision-making, it was also shaped by practical constraints such as time, funding, and varying levels of participation.

I also acknowledge the limitations of being an outside researcher and the broader concerns raised in relation to epistemic injustice when non-autistic people conduct autism research (Walker, 2021). However, as Thompson-Hodgetts (2022) reflects, there is space for both autistic and non-autistic researchers, particularly in collaborations where there is sustained attention to positionality and a willingness to be challenged by lived experience.

Rather than resolving these tensions, I accept them as part of the research process. My position as a non-autistic researcher is neither neutral nor easily overcome. In this context ‘not knowing’, can present me with an opportunity for knowledge creation and inquiry

(Jackson-Perry, 2025), but it does not remove the asymmetries of being a non-autistic researcher doing autism research. Reflexivity therefore remains essential, not as a tool to resolve tensions, but as a commitment to ongoing attentiveness to what remains outside my lived experience.

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Appendices

Appendix A

External Grants and Awards

The adoption of participatory research methods in this project developed from its ontological and epistemological approaches. Adding autistic perspectives to the investigation of loneliness, was important to address a gap in research, as pointed by the results of the first study (systematic review) and to reduce epistemic injustice (Krawczyk et al., 2025). Quality participatory research happens when people are enabled to take an active role in shaping research. This means that the researcher is responsible for promoting enabling environments, accessible language and adequate payment for collaborators' contributions (Fletcher-Watson et al., 2021). Unfortunately, the institutional research funds available for this PhD project was not enough to fully support fair payment for participants' time and expertise. Therefore, after completing the systematic review and understanding the need for extra funding, external grants were sought and secured specifically to support autistic participation in the project.

The Waterloo Foundation

The Child Development Fund (Ref no. 3876-7705) offered by the Waterloo Foundation added £804 (eight hundred and four pounds) to the research project. The strategy used to secure funding, was to approach several charities, foundations and research institutions involved in autism research, show the commitment of the project with participatory methods and the justification for extra funding. The proposal explained how the funds would be used to promote participatory data analyses. The Waterloo Foundation were interested in the project and acknowledged the increasing importance of loneliness and mental health. They praised the focus on participatory research and the foresight of a PhD student to hunt for additional funding. The small grant was allocated within one of their

bigger research grants. Details about how sessions of participatory data analyses were conducted can be found in Chapter Four.

The Organization for Autism Research

The Graduate Grant Competition is promoted annually by the Organization for Autism Research. It offers up to U$2000 (two thousand dollars) to doctoral candidates through a one-step application and review process. The grant is to fund studies that produce practical outcomes, lead to happier lives and are aimed at independent research studies only.

The proposal submitted for review included a cover letter, an abstract, research background information, timeline for the project, methodology and evaluation, outcome recommendations, practical relevance, subject protection, a budget and a letter of support. It outlined the theoretical development of the loneliness scale for autistic young people with participation of autistic young people and their communities. The funds allowed members of the autistic community to collaborate with the refinement of the scale items, formatting and response range of the scale. This was completed through several rounds of consultation and is detailed in Chapter Five.

2025 Autism CRC Award

The research project was awarded the 2025 Autism CRC Best PhD Student Award for Achievement in Autism Research in the category Student-led project: inclusive research practice. Autism CRC are an independent national source of evidence in Australia (Autism CRC, 2025). They produce evidence-based resources and guidance for the Australian government, health professionals and the community. Winners of the 2025 Awards were officially announced during the annual Asia Pacific Autism Conference. The organisers described the project as impactful, praising the engagement with autistic co-producers and acknowledging its significance for the autistic community.

This appendix included instances when this research project was well accepted and supported by funding agencies and research communities, being recognised as relevant and significant for the autistic community. Financial support from external funders meant that autistic young people and members of their communities were enabled to collaborate to the project.

Appendix B

Copy of Study Two's Pre-Registration Form on Open Science Framework (OSF) Online Platform

Metadata

Title

Autistic and not lonely: A creative and participatory exploration of how autistic adolescents experience loneliness and share their personal resources of connection and wellbeing

Description

This project is part of a PhD thesis that aims to investigate experiences of loneliness for autistic adolescents. I am also interested in exploring autistic led resources that promote connection and wellbeing.

Contributors Luciana White, Stephanie Petty, and Emma Tecwyn

Category Project

Affiliated institutions

No affiliated institutions

License

No license

Year

2024

Copyright Holders

No copyright holders

Subjects

- Psychology
- Social and Behavioural Sciences
- Arts and Humanities
- Developmental Psychology
- School Psychology
- Other Psychology

Tags

- Autism
- Autism and loneliness
- Autistic adolescents
- neurodiversity

Study Information

Research Aims

This project is part of a PhD thesis that aims to investigate experiences of loneliness for autistic adolescents. I am also interested in exploring autistic led resources that promote connection and wellbeing. I chose a qualitative design due to its suitability for gaining insights of lived experience (Austin and Sutton, 2014). The project is based on participatory research guidelines (Chown et al., 2017), and I will use creative and flexible methods of data collection. These were reviewed and validated by autistic people through PPI (Patient and

Public Involvement) groups before the study was designed. Flexible methods aim for inclusivity, catering for the diversity of communication styles and promoting an enabling environment (Ridout, 2017). According to Milton (2012) research anchored on the dichotomy between normal and abnormal individuals has promoted outcomes that failed to prioritise the subjective experience of autistic people. I believe a qualitative approach with a participatory framework can offer a conceptualisation of what loneliness is from an autistic point of view, contributing personal voice to literature, in line with the neurodiversity paradigm (Kapp, 2020).

If helpful, please select the type of aim (non-exhaustive list):

Exploring

Research question(s)

How do autistic adolescents experience and understand loneliness? What personal strategies promote feelings of connection and well-being?

Anticipated Duration

Start date 02/2024 End date 12/2024

Design Plan

Study design

This is a qualitative, exploratory study.

Sampling and case selection strategy

Participants will include autistic adolescents, with or without learning difficulties, ranging from 12 to 18 years of age, with a formal diagnosis of autism. For this project, I will initially aim to recruit between 20 to 30 participants. These numbers are based on Green & Thorogood's (2004) suggestion that little new information is generated after interviewing 20

people. However, since the methods for this project are not solely interviews, the sample size could be increased or decreased based on the following factors: - Data must allow for rich and textured understanding of the phenomena of loneliness (Sandelowski, 1995). - Dataset should allow the researcher to manage the complexity of the analysis, considering the scope and resources available for this project (Ritchie et al., 2003) - Usable data will be assessed for quality rather than quantity (Morse, 2000). Participants will be recruited through: - Contacting gatekeepers directly (gatekeepers might include personnel from schools and alternative education providers, e.g., headteachers, deputy headteachers, designated safeguarding leads, SENcos, etc.) - Advertising within in-person and online support groups. - Directly inviting parents of autistic adolescents who have expressed interest in participating further in research when involved in one of the PPI panels for this project. - Snowballing – asking participants to recommend other participants that would be interested in taking part.

Data Collection

Data source(s) and data type(s)

Original data will be collected for the current study in the form of written comments and transcription of interviews and art-based groups.

Data collection methods

Data collection methods were carefully considered based on the nature of the topic and the aim of the research. Facilitating participants' engagement was also an important part of how methods were chosen. Below a list of the methods and their suitability for this project:

- Semi-structured interviews with object elicitation – this method can soften conversations about life experiences (Willig, 2017), where the objects become bridges between the participant and their experience. Silver (2013) also points out that this approach encourages participants' agency, and it helps them to make sense of their experiences without having to

rely solely on language. Both points are valuable for this project, the first is aligned with the neurodiversity paradigm and the latter as an important consideration for individuals who might need support with verbal communication.

Details about semi-structure interviews: Participants will be asked open ended questions related to their experiences of loneliness, guided by a semi-structured protocol and prompts. Meaningful pictures, objects and drawings, brought by the participant, can be used to elicit ideas and to enrich the conversation. Interviews will be audio recorded and later transcribed for analysis. Recordings will be deleted once transcription is completed.

- Art based sessions and a virtual wall of thoughts - these methods are again an attempt to harness participants' interest by offering forms of engagement that will be more inclusive, avoiding singular approach methods that are guided by neuronormative expectations (Ridout, 2017). Details about the Virtual wall of thoughts – This works like a virtual notice board. It will be hosted on Padlet. Participants will be given a code of access and will be asked to post comments and/or pictures related to their experiences of loneliness. Prompts will include 'I feel lonely when...'; 'I feel connected when...'; 'Being lonely is...'; 'Being not lonely is...'

- Details about the Art based session – participants will be provided with art supplies (paints, collage materials, glue, scissors, felt tip pens, crayons, pencils, etc.) and will be invited to create a collage, a painting, a drawing, or an art composition that can be a starting point for a conversation about their experiences of loneliness and/or connection. Participants will also be able to use digital art for these compositions. Conversations will be audio recorded and later transcribed for analysis. Recordings will be deleted once transcription is completed.

In addition to considering suitable methods, all efforts will be made to accommodate needs of participants who wish to take part in the research. This will include (but not be limited to): - having someone to facilitate communication and/or interaction.

- offering printed versions of questions and/or prompts.

- offering extra time for participants to formulate answers.

- adopting alternative means of communication.

- softening sensory stimuli in the room when possible.

- offering regular breaks.

- breaking up one session into smaller sessions.

Data collection tools, instruments or plans

Semi-structured interview protocol

Walls of thoughts hosted on Padlet

Conversations generated by art-based activity.

Semi-structured interview_SP_LW.docx

Stopping criteria

For this project, I will initially aim to recruit between 20 to 30 participants. These numbers are based on Green & Thorogood's (2004) suggestion that little new information is generated after interviewing 20 people. However, since the methods for this project are not solely interviews, data collection could be increased or decreased based on the following factors:

- Data must allow for rich and textured understanding of the phenomena of loneliness (Sandelowski, 2000).

- Dataset should allow the researcher to manage the complexity of the analysis, considering the scope and resources available for this project (Ritchie et al., 2003)

- Usable data will be assessed for quality rather than quantity (Morse, 2000).

Analysis Plan

Data analysis approach

Once data collection is completed, reflexive thematic analysis will be used to go beyond the experiential phenomena, contextualising participants' perspectives (Braun & Clarke, 2022b) and offering insights into the social processes surrounding loneliness, disability and inclusion.

Data analysis process

The analytical process for this project is based on a relativist epistemology, guided by a participatory and inclusive framework, and anchored in the recent ontological shift in autism research. The relativist orientation is concerned with developing alternative conceptualisations of loneliness for autistic adolescents, rather than looking for one single truth, usually sought by positivist methods (Burr, 2015). The use of a participatory and inclusive framework promotes the recognition of a social model of disability that includes and values autistic voices and lived experience in research (Milton, 2017). Finally, the ontological shift in autism research is a departure from the positivist epistemology and the neuropsychological lens which has dominated research and healthcare contexts (Pellicano & den Houting, 2022; Petty et al., 2023). It proposes a more nuanced understanding of autism that sees it rather than a pathology, as a neurological difference which can be presented in multiple ways (Milton, 2017). The following data analysis process is based on Braun and Clarke's (2022b) conceptual and design thinking for thematic analysis. Steps in the analysis: - The main investigator (LLW) will personally collect data. - Once data collection is finished, interviews and conversations from art-based sessions will be transcribed. Data collected from the virtual wall of thoughts will be collated into one single document for ease of management. - LLW will get familiarised with the dataset by reading through it several times and adding notes to the margins. - Time and space for reflection will be considered as an

essential step in the analytical process. - LLW will inductively code the dataset. The coding process does not occur all at once. It shifts and changes with the development of the researcher's interpretation of the dataset. Codes can be split into more codes, they can be redefined, expanded or collapsed. - Codes will then be grouped into themes according to patterns of meaning anchored by shared ideas or concepts. - Themes will be discussed with the supervisory team (SP and ET) for enhanced reflexivity and interpretative depth. - Analytic observations will then be contextualised in relation to existing research to report the themes developed.

Credibility strategies

- Reflexivity

Please provide a short rationale for why you selected particular strategies and how they are appropriate given your study's aim(s) and approach or specify your credibility strategies if not on the above list.

Reflexivity - The quality assessment of this project will not be focused on determining the accuracy with which coding was done or how themes were identified. Following Braun and Clarke's (2022b) guidance to assure quality, I will be focusing on reflecting about the research process, being rigorous in how I conduct each step and making sure that these are reported clearly and committing to a great depth of engagement with the dataset and the analytical process. Reflections about the research process will include questions about my personal positioning and values and my assumptions and expectations about the topic of my research. I will also be thinking about my relationship with participants (personal reflexivity). Interrogations around methodological choices (functional reflexivity) and epistemological and theoretical positioning (disciplinary reflexivity) will also be part of quality assurance. To accomplish this, I will keep a reflexive journal throughout the process, where I intend to record my reflections and insights.

Appendix C

Semi-structured Interview Protocol Used to Support Interviews During Study Two

Semi-structured interview

Objectives

In this research we are interested in understanding loneliness, such as what loneliness means to you, if you feel lonely, if so, how you experience loneliness and if you have any personal ways in which you tackle feelings of loneliness.

Familiarity with the feeling of loneliness

Have you ever felt lonely?

- Prompt -Is it a positive or a negative feeling?

Conceptualisation of loneliness Here, the objective is trying to find out if loneliness is linked to the number of relationships (social loneliness), quality of relationships (emotional loneliness) or to feelings of not belonging, not being understood (existential loneliness).

What does loneliness mean to you? How would you describe loneliness?

Can you give me an example of when you felt lonely?

- Prompt - Can you describe the thoughts you had?
- Prompt - Can you describe the emotions you felt?

How often do you feel lonely?

- Is there a pattern for your feelings of loneliness?

What makes you feel lonely?

- What things contribute to feelings of loneliness?

- Are there people, objects, places, activities that contribute to this feeling?

Conceptualisation of nonlonely

What is the opposite of loneliness?

Can you give me an example of when you felt like that?

- Prompt - Can you describe the thoughts you had when you felt [use participant's words]?
- Can you describe the emotions you felt when [use participant's words]?

How often do you feel [participants' words]?

- Is there a pattern to this feeling?

What makes you feel [use participant's words]?

- Are there people, objects, places, activities that contribute to this feeling?

Object / image elicitation

Ideas adapted from: Willig, C. (2017). Reflections on the Use of Object Elicitation. *Qualitative Psychology*, doi: 10.1037/qup0000054

Thank you for bringing this.

Can you tell me what it is?

- How does it work?
- When do you use it?

What does it mean to you?

Why did you decide to bring it today?

- How is this object / image significant to you?

What was it like to choose these objects?

Appendix D

Example of Interview Edited Manually After Automatic Transcription

Date: 23/05/2024 ; Duration: 17 minutes and 24 seconds

LLW:	Okay. So, Max, are you okay if I sit here?
Max:	I do not mind.
LLW:	Okay, that's fine then. So, tell me something, have you ever felt lonely?
Max:	Yeah.
LLW:	Yes? And do you think that is a positive feeling or a negative feeling?
Max:	Negative.
LLW:	Negative. So, when you feel lonely, what kind of emotions or (.) behaviours come with the feeling of loneliness? What do you feel like doing?
Max:	Bored.
LLW:	You feel bored. So, every time you feel lonely, you feel bored.
Max:	Mmm.
LLW:	Okay, can you think of one time when you felt lonely?
Max:	((pause)) I felt a lot of times lonely, uuuum
LLW:	Is that something that happens often?
Max:	A few times.
LLW:	A few times. So, would you say you felt lonely this week or last week?
Max:	No, not in the weeks now.
LLW:	No. Okay, and can you remember one time when you felt lonely?
Max:	Uuuummmm. No.
LLW:	No. Okay, were you with people or were you without people at the time?
Max:	Without.
LLW:	Without people. So, when you feel lonely, would you say that that feeling is connected to the presence or absence of people?
Max:	Yeah?
LLW:	Yes, okay.
Max:	That's the definition of loneliness.
LLW:	Yes, that's what I'm trying to find out for autistic people, if it's the same definition. Do you think it is?
Max:	It should be.
LLW:	Do you think that autistic people feel lonely the same way as non-autistic people?

Max: Probably.

LLW: You think so? Yes, that's what I'm trying to find out. That's why I'm asking these questions that seem a bit (.) I don't know, maybe obvious?

Max: Well, loneliness is the thing where you don't really talk to people, and you just sit there doing nothing.

LLW: Doing nothing?

Max: Waiting.

LLW: Waiting for what?

Max: Waiting for someone.

LLW: And that is definitely a negative feeling, yes?

Max: Yeah.

LLW: Okay, and what is the opposite of loneliness? And when you're not, I'm trying to find that word, I don't have a word for that yet. So, when you're not feeling lonely, what are you feeling?

Max: Uuuum ((pause)) Happy.

LLW: Happy, okay. And when you're feeling happy, what do you have around you?

Max: People.

LLW: What is your experience of happy?

Max: Friends.

LLW: Friends, people.

Max: Um-hum

LLW: Is there anything that you do with these friends or people that make you happy?

Max: No?

LLW: No, so does it mean

Max: I just talk to them.

LLW: You just talk to them. Is there a particular, um, topic, that you like talking to them about?

Max: No.

LLW: No, okay. Do you have lots of friends at the moment?

Max: No.

LLW: No. In school, do you have people who you can talk to?

Max: (.) Sometimes.

LLW: Sometimes. Are they your own age or are they, would you say they're older, like members of staff?

Max: In between.

LLW: In between, okay. What about at home? Can you talk to people at home?

Max: No.

LLW: Not really? Why is that?

Max: ((pause)) Because I normally don't have anyone over at home.

LLW: Okay, who do you live with at the moment?

Max: Kass, mum, George, that's it.

LLW: Okay, do you ever feel lonely when you are with your family?

Max: Sometimes.

LLW: Okay, so you told me that when you have people around you-

Max: No, I said when I'm talking to people or doing something with people.

LLW: Oh, right. Okay, so when you're talking to people or doing something to people, that's when you feel the happiness, that it's the opposite to loneliness.

Max: Um-hum

LLW: So, is that why sometimes at home you also feel lonely? Because although you are surrounded by people, you're not necessarily talking to them or doing things with them.

Max: Umm, yeah.

LLW: Is that true?

Max: Yep.

LLW: Okay, very good. And do you think that there are other things that make you feel happy or not lonely that are not connected to people? So, are there any objects or activities or games or anything that you do that make you feel happy or connected?

Max: Mmmm ((long pause)) I do have a few games.

LLW: Okay, tell me about them. What games do you like?

Max: Well, they have voice chat, so you can talk to people.

LLW: Oooh, that's very interesting. So, when you are playing those games and you are chatting to those people who are playing, do you ever feel lonely?

Max: No.

LLW: No, you're quite happy just chatting to these people. Do you know them personally?

Max: No.

LLW: No, you just chat to them online, so you don't know how they look like?

Max: No.

LLW: And you're quite happy to (.) um, have this kind of connection. Do you, do you, let me rephrase that. So, when you are talking to these people online, do you feel you still need people around you to talk to? Or, is that quite enough for you to feel happy?

Max: Mmm ((long pause)) Well, when I'm talking to them, then, yeah, it's fine.

LLW: And then as soon as you leave the game, then it's when you need it or you need other people or then you're okay as well?

Max: When I leave it, then I'm, then I just leave it, I just sit down.

LLW: Okay, so you not necess-, do you need people then after that?

Max: No.

LLW: No, you're all right.

Max: I've had enough of people probably.

LLW: Okay, that's interesting as well. So, when you come from school, for instance, I suppose you are surrounded by people in school, are you?

Max: Mm, yeah.

LLW: Do you feel lonely there?

Max: (.) No.

LLW: No? So, you do talk to people there?

Max: Yeah.

LLW: Yeah, so when you're talking to people there and you're surrounded by people, you don't feel lonely.

Max: Mm-hum

LLW: But then do you get enough of it? You know, you get to a time where you say like, "oh, okay, enough of people, I need some time on my own."

Max: That's why there's the end of the day.

LLW: Okay, and then when you get to the end of the day?

Max: Then I go back home.

LLW: And then at home, do you prefer, do you need some time on your own?

Max: Yeah.

LLW: Yeah, that makes you feel good.

Max: Um-hum

LLW: Good, fantastic. So, you have your games that you told me. Are there any TV shows that you watch that make you feel happy and connected?

Max: No.

LLW: Not really? You don't watch telly?

Max: I mean, I do watch stuff, but I just watch it because I'm normally just bored, and I don't know what to do.

LLW: Okay. Do you, um, have contacts online, for instance, like WhatsApp or do you message people and friends?

Max: Well, I had WhatsApp, but ((pause)) my phone is gone now.

LLW: Yes. So, but before your phone was gone, did you use WhatsApp a lot?

Max: Yeah.

LLW: And how did that make you feel? Have you ever felt lonely using WhatsApp?

Max: No.

LLW: Yes or no?

Max: No.

LLW: No. Okay. Oh, this noise. Let's wait for the noise to go.

Max: But it's gone.

LLW: Yes, good, isn't it? Very good (.) So, so there's the telly. We asked you about the games.

What about objects or things that you have at home or that you carry with you? Do you have anything that makes you feel happy and that stops you from being lonely?

Max: Nope.

LLW: No, you don't have anything like that?

Max: Not really.

LLW: No. Is there a space, a room, a place that makes you feel happy and connected?

Max: No.

LLW: No. So for you, connection and happiness is when you are with people, talking to them and doing something with them.

Max: Mm-hum

LLW: Would that make sense? Would that be fair to say?

Max: ((pause)) Mm-hum

LLW: But you don't necessarily (.) need to know them personally?

Max: Not all the time.

LLW: Not all the time. So that exchange that you have online when you're playing games, would you say that's enough?

Max: Mm. Yeah.

LLW: Yeah? (.) Okay. So, let's imagine a scenario and say that for the next, I don't know, five days, you're just going to play games and you're going to talk to people online and you're not going to go to school or meet anybody and you won't have any kind of interactions with people. Would that be enough for you?

Max: Mmm

LLW: Or would you want to meet people?

Max: It would probably be enough for me.

LLW: You probably need to meet people, yeah? Or maybe not.

Max: Not necessarily.

LLW: Not necessarily. And why not?

Max: Because mmm ((pause)) well, I do still have my family members to talk to.

LLW: Um-hum

Max: So

LLW: And that's enough?

Max: Yeah.

LLW: Okay. When you're chatting on the game, what, what do you talk about? Do you talk about the game? Do you talk about other things?

Max: Ummm ((pause)) random stuff.

LLW: Random stuff? Can you give me an example?

Max: Mmm, like bugs in the game.

LLW: Mm-hum

Max: Just having fun.

LLW: Mm-hum

Max: That stuff.

LLW: That kind of thing.

Max: Mm-hum.

LLW: That's amazing. That's good. Excellent. Right. I think I have asked you everything I needed to ask you about your experience. But I am more than happy for you to add anything else. Is there anything else that you can say?

Max: But

LLW: Yeah? Go on.

Max: All people are the same, so ((pause)) why are you asking for this?

LLW: Why am I asking for this? What do you mean?

Max: Well, you wanted (.) someone who's autistic to come here to get info on if they're lonely or not.

LLW: And if they're lonely or not, I want to know how they experience loneliness.

Max: Not all people experience loneliness in the same way.

LLW: Well, that's what I'm trying to find out because all the studies so far-

Max: I use my imagination a lot.

LLW: Do you? Right. And how, how do you use your imagination a lot?

Max: ((pause)) Imagining (.) people.

LLW: Okay. So, you imagine people. And do you talk to these imaginary people?

Max: No.

LLW: No, they’re just

Max: I normally just play as them.

LLW: And they're just in your head, are they?

Max: Mm-hmm.

LLW: Okay. Are they people your own age or are they (.) older people, younger people?

Max: I haven't configured that yet.

LLW: Okay. Do they have names?

Max: No.

LLW: No. Are they always the same people or are they different people?

Max: Sometimes different, sometimes not.

LLW: Okay. And when you imagine these people. So, when you're using, you said that you use your imagination a lot. When you're using your imagination, do you feel lonely ever?

Max: Not really, no.

LLW: Oh, I see. That's really interesting. You see, that is something different that we don't hear from non-autistic people. And the studies, they are telling us that autistic people feel exactly the same as non-autistic people. So, this is what I'm trying to find out. Because they keep telling autistic people that they need to learn social skills, that they need to do this and need to do that, not to feel lonely. But do you actually need to do all that or do you have your own strategies? You're telling me, "I use my imagination". Why is that bad? Do you think that's bad, using your imagination?

Max: No.

LLW: You see, so that's a good thing.

Max: I used to dream a little bit ((pause)) it's using your imagination in your dreams.

LLW: That's cool. And do you do that, um, on a regular basis?

Max: No.

LLW: No. When do you tend to use your imagination?

Max: ((pause)) Whenever I want. It's my brain.

LLW: Yes? So, is it when you are out of your game, for instance, or when you're feeling bored, or when you are on your own?

Max: When I'm bored and I'm on my own.

LLW: And then you use your imagination to create these people.

Max: Mm-hum

LLW: That's really interesting. Really, really interesting. Do you want to tell me anything else about your imagination, your use of imagination, or other strategies that you use that you think I would be interested in?

Max: A lot of autistic, a lot of autistic people do use their imagination sometimes.

LLW: Yes, they do (.) Yes, they do. And do you think that's a good thing?

Max: Mmm, sure.

LLW: Do you have any feelings associated to your imagination use?

Max: Not really.

LLW:	No. Do you feel positive about it?
Max:	Yeah.
LLW:	Yes, you feel positive about it. Do you feel relaxed when you are using your imagination?
Max:	Sometimes.
LLW:	Okay, do you imagine things that maybe distress you?
Max:	No.
LLW:	No. Only things that soothe you?
Max:	Yeah.
LLW:	Yeah? Would you be able to describe one of the people or one of the things that you imagine?
Max:	A chair.
LLW:	A chair? Okay, and how is that chair?
Max:	(.) Mmm ((pause)) I haven't gotten to the details.
LLW:	You haven't gotten to the details (.) Okay, right. This is very, very interesting. Okay, so anything else that you would like to add?
Max:	Mmm ((pause)) no.
LLW:	No? Are you happy for me to stop the recording?
Max:	Mmm, sure.
LLW:	That's it. Press that button.

Appendix E

Table of the Domains of Loneliness and Definitions Presented to Experts During Evaluation of Content Validity

Dimension	Definition
Global Loneliness	A general feeling of isolation or disconnection that includes overlapping emotions related to different dimensions of the construct. Global loneliness might be expressed with more generic words.
Social loneliness	A feeling of having an inadequate number of relations or an insufficient social network.
Emotional loneliness	A perceived lack of closeness in relationships.
Existential loneliness	A feeling of being separated from what is conventional or universal due to feeling different from others. An absence of belonging and/or feelings of alienation (i.e., I am different therefore I do not belong)
Experiential loneliness	A perceived lack of connections due to experiencing the world differently from others. (i.e., My unique experiences, including how I sense the world, interfere with how I connect to others and vice-versa).
Positive aloneness	A feeling of contentment and self-sufficiency when alone.

Appendix F

Materials Used to Present the Research Project to Participants Who Took Part of the Development of the ELSA

Traditional investigation of loneliness **X** **Loneliness for autistic young people**





Global Loneliness

A sense of general loneliness. A general feeling of isolation or disconnection that includes overlapping emotions.



Social Loneliness

When we are unhappy with the number of friends we have.



Emotional Loneliness

When we are unhappy with the quality of our friendships.



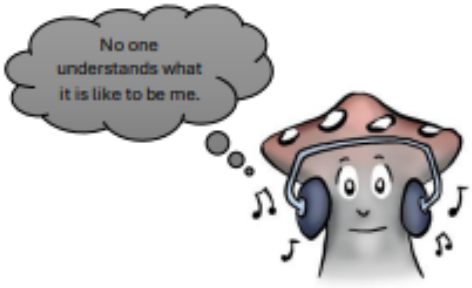
Existential Loneliness

When you feel separated from the world as if you were not part of it for being too different or misunderstood.



Experiential Loneliness

When we feel people do not understand our experiences. When you feel no one else shares the same experiences you live.



Positive Loneliness

When lonely, you feel you can concentrate better at things that are important for you. It's a time for self-improvement and self-enjoyment.



Illustrator: Matthew Cole (www.mattcoleillustration.co.uk)

Appendix G

Example of Sheet with Candidate Items Presented to Participants Who Participated in Focus Groups

Name: _____

Experiential Loneliness (1)

My anxiety makes it difficult for me to be social.

Very important	Important	Relatively important	Slightly important	Not important

I have people who understand what it is like to be me.

Very important	Important	Relatively important	Slightly important	Not important

I feel I can communicate well with people.

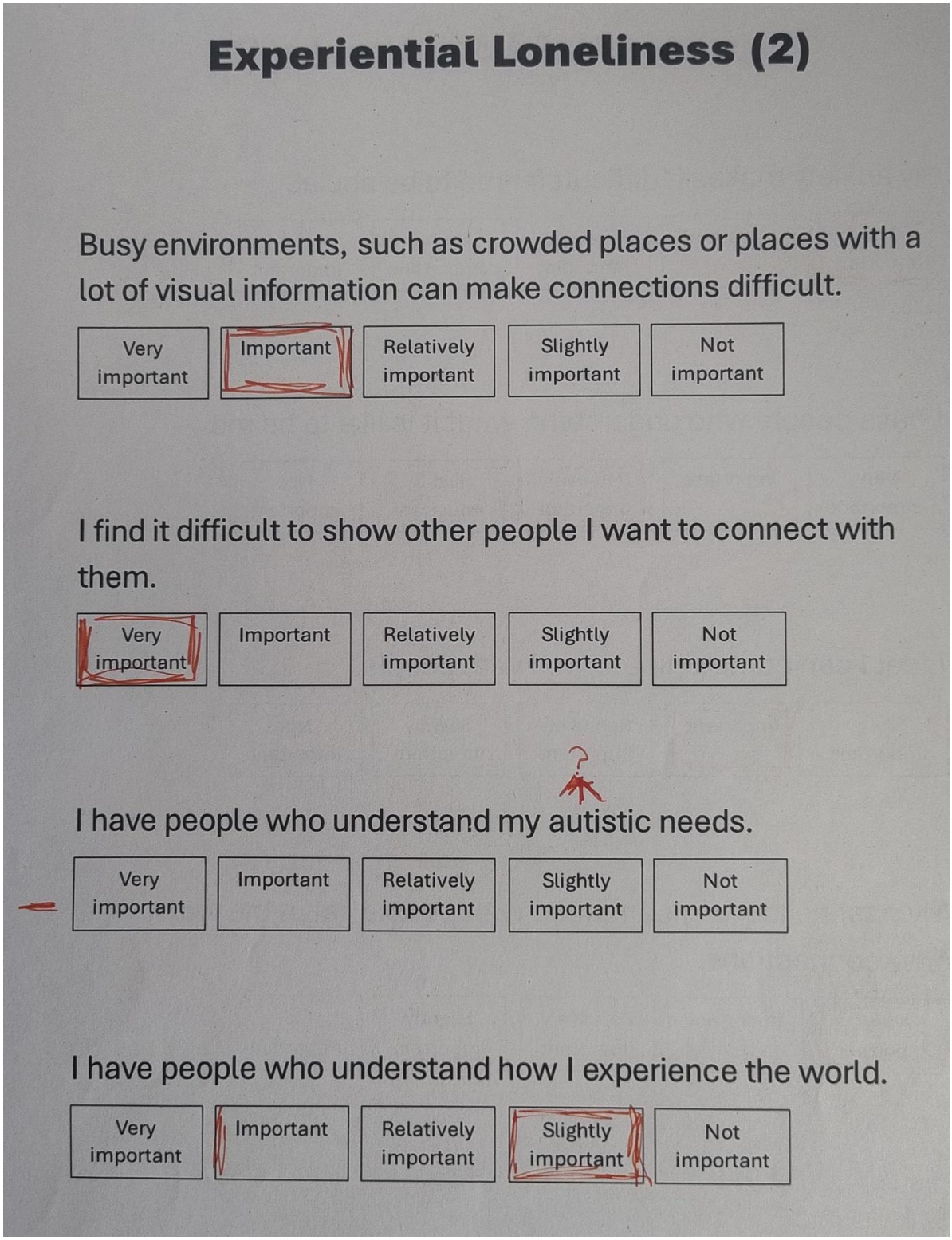
Very important	Important	Relatively important	Slightly important	Not important

My past negative experiences with people get in the way of new connections.

Very important	Important	Relatively important	Slightly important	Not important

Appendix H

Three Examples of How Participants Recorded their Views When Evaluating Candidate Items for the ELSA



Emotional Loneliness (1)

I have people who I feel close to.

Very important	Important	Relatively important	Slightly important	Not important

I have people who want to listen to me.

Very important	Important	Relatively important	Slightly important	Not important

I have people who are interested in my wellbeing.

Very important	Important	Relatively important	Slightly important	Not important

I have people I can talk to about things that bother me.

Very important	Important	Relatively important	Slightly important	Not important

I feel I have people who are there for me if I need anything.

Very important	Important	Relatively important	Slightly important	Not important

I need help with my emotions from people around me?

Positive aloneness (1)

I feel less lonely when I can be an observer (e.g., watching people playing a game or have a conversation; or listen to family members go about their day).

Very important	Important	Relatively important	Slightly important	Not important
		✓		

When my senses are stimulated, I do not need other people.

Very important	Important	Relatively important	Slightly important	Not important
			✓	

I enjoy being mentally engaged on my own.

Very important	Important	Relatively important	Slightly important	Not important
				✓

I enjoy time alone.

Very important	Important	Relatively important	Slightly important	Not important
			✓	

I like being around people but I find it overwhelming when there is too many people.

I like being with others.

Very important	Important	Relatively important	Slightly important	Not important
✓				

FEEDBACK: MORE PICTURES, LESS WORDY.

Appendix I

Protocol for Cognitive Interviews Conducted During Pre-Testing of the ELSA

Protocol for Cognitive Interviews

Candidate items are divided into 5 separate sections, with approximately 10 questions each.

Each section has mixed items from different domains of loneliness.

Once a section is completed, the participant is prompted by the researcher about that section.

Participants can choose to respond as few or as many sections as they feel comfortable with.

Sections will be administered randomly, making sure that every section gets answered the same number of times.

Researcher to make notes of non-verbal cues given by participants:

- skipped items
- items that take longer to respond
- participant losing focus
- participant going backwards and forwards between survey items
- participant changing their mind over answers
- participant looking for content on the back of the page or elsewhere
- participant making notes on the page or underlining words

Prompts:

Start with open questions:

- What would you like to tell me about this first section?
- Any general comments about the items in this section?

(Give participants time to think and answer)

- I've noticed you took your time to answer this question.

  Could you let me know why?

  Were there any words that were unclear to you?

  What does the term "…" mean to you?

  What do you think the question was trying to find out about you?

- I've noticed you skipped item x:

  Could you tell me why?

  Was that item difficult to understand?

  What do you think the question was trying to find out about you?

- I've noticed that you changed your answer here.

  Would you mind sharing your thought process?

  Did you think about a different meaning for this question when you changed your mind?

  Does the question make sense to you now that you have changed your mind?

- I've noticed you made some notes/drawings...

  Would you mind sharing them with me?

  What do they mean?

- If participants show signs of tiredness or of cognitive overload:

  Are you finding this difficult to complete?

  Is this item difficult to understand?

Are you okay to continue? / Would you like a break?

Prompts at the end of each section:

- Did you have problems understanding any of the questions?
- Were there any questions that were difficult to answer?
- Were there any words that you did not understand?
- Were there any questions that you think are not important to measure loneliness? Why?
- Did you find the questions are relevant to your experience?
- How often did you feel like answering “this does not apply to me”?

Prompts at the end of the interview:

- What did you think of the response options?
- What did you think of the visual cues for the response options?
- Does this style of presentation work for you?

  What did you think of the font?

  Is the space between items good?

- Do you have any suggestions to improve the visual presentation of the questionnaire?
- Is there anything that would have made it easier for you to answer this questionnaire?
- Did you at any point feel overwhelmed by the questions?
- Do you have any other comments?

Appendix J

First Version of the ELSA

ELSA

Experiences of Loneliness – Scale for Autistic Young People

Why are you doing this?

We are interested in understanding your experiences of loneliness and connection.

There are no right or wrong answers.

How to respond:

Please read each statement carefully and indicate how much it applies to you.

For each statement circle the answer that best represents how true the statement is to your experience.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

If a question does not apply to you, circle "not applicable".

If you prefer not to answer a question, circle "I prefer not to answer".

Your answers are confidential.

1. I have people I can talk to about things that bother me.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

2. I feel lonely.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

3. I have people who care about me.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

4. I feel misunderstood.

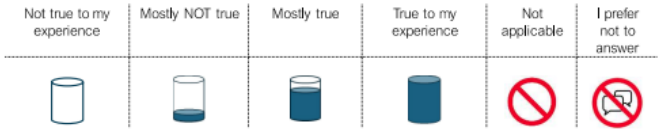
Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

5. I have people with whom I can do day-to-day activities.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

Comments:

6. I feel different from what is expected of people my age.



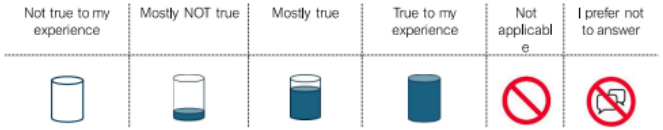
7. I feel that others want my company.



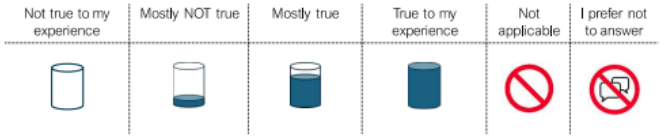
8. I like being on my own in safe spaces.



9. I have people in real life I like to be around



10. Busy environments can make connections with other people difficult.



Comments:

11. I like being with people I know.



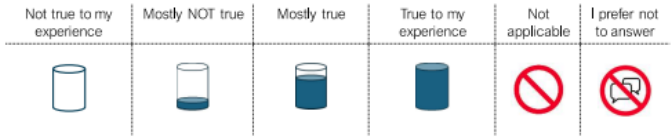
12. I have people who are happy to listen to me.



13. I find it difficult to be social.



14. I have people who are interested in my wellbeing.



15. I prefer engaging with personal interests than being with other people.



Comments:

16. I feel emotionally low.



17. I know how to start conversations when I am in a group of people.



18. I have deep personal connections.



19. I feel comfortable alone when my senses are stimulated.



20. I find it difficult to get to know people out of school or college.

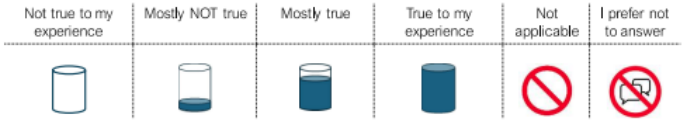


Comments:

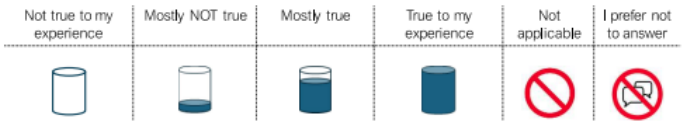
21. I fit in with other people.



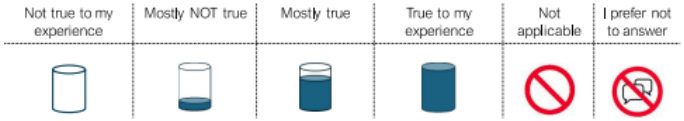
22. I feel I am accepted as I am.



23. I have people I can talk to and have a good time with.



24. I don't want to be around people that often.



25. I feel overstimulated when involved in social activities.



Comments:

26. I would like to have more people to talk to everyday.



27. I have enough people in real life who make me feel good about myse



28. Being around people is enough for me not to feel lonely.



29. I am happy with the number of friends I have at the moment.



30. I can be myself around people I know.



Comments:

31. I feel there are other people like me.



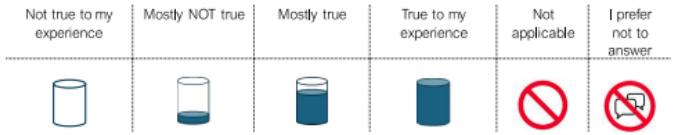
32. I have people in real life who I feel comfortable with.



33. I feel less lonely when I connect to fictional characters (in movies, books, series, etc.)



34. I prefer online interactions.



35. I can make new friends independently.



Comments:

36. I have people who can give me emotional support.



37. I feel connected to someone when we have the same interests.



38. I have places where I can be myself.



39. I have pets that are like friends.



40. I feel I can communicate well with people.

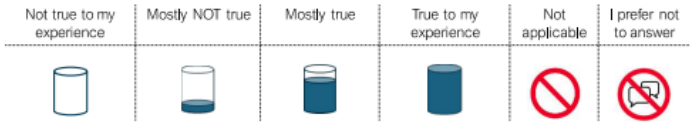


Comments:

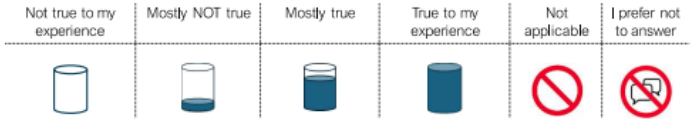
41. I find it difficult to connect with people who are the same age as I am



42. I prefer face-to-face connections.



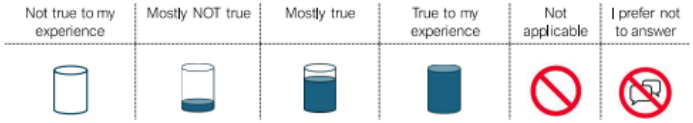
43. I feel alone within my community.



44. I feel I have to hide my true self most of the time.



45. I have important objects that help when I feel lonely.



Comments:

46. I know people in real life who understand me.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

47. I have people in real life who I feel emotionally close to.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

48. I am liked by people who are important to me in real life.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

49. I feel I am included by people who are my age.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

50. I feel judged by other people.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

Comments:

51. I feel fulfilled when doing activities by myself.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

52. I like being alone.

Not true to my experience	Mostly NOT true	Mostly true	True to my experience	Not applicable	I prefer not to answer
					

Comments:

Appendix K

Second Version of the ELSA

ELSA

Experiences of Loneliness – Scale for Autistic Young People

Why are you doing this?

We are interested in understanding your experiences of loneliness and connection.

There are no right or wrong answers.

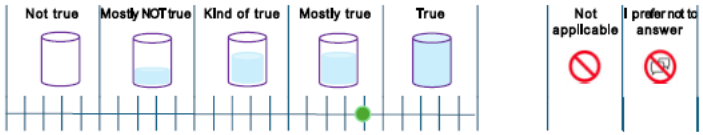
How to respond:

Please read each statement carefully and indicate how much it applies to you. Your answers should be based on how you are feeling today.

For each statement place a mark on the line indicating the answer that best represents how true the statement is to your experience.

For example:

I enjoy talking to my friends face-to-face.

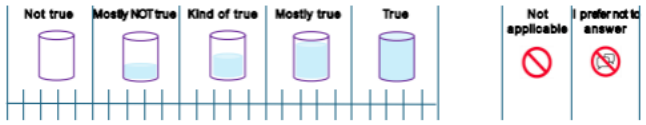


If a question does not apply to you, circle "not applicable".

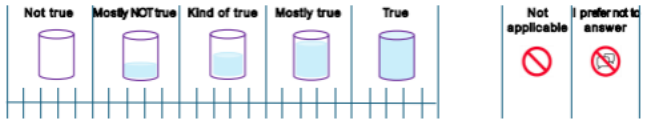
If you prefer not to answer a question, circle "I prefer not to answer".

Your answers are confidential.

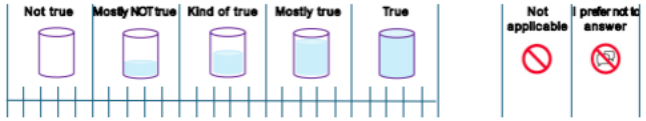
1. I have people I can talk to about things that bother me.



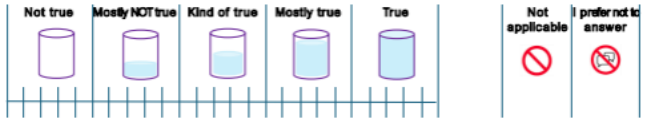
2. I feel lonely.



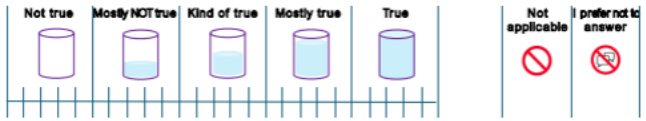
3. I have people who care about me.



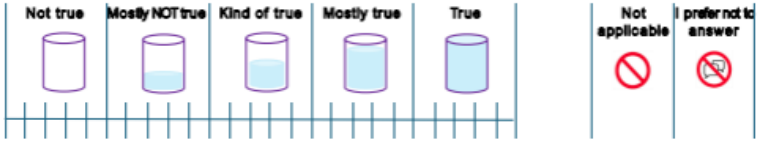
4. I feel misunderstood.



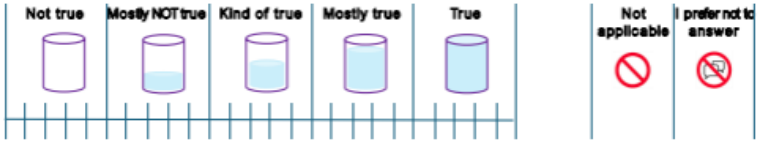
5. I have people I can do everyday activities with (e.g. having lunch, going to and from school/college, studying, playing videogames, going to clubs, etc.)



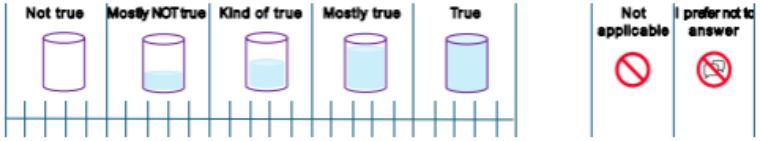
6. I feel different from what is expected of people my age.



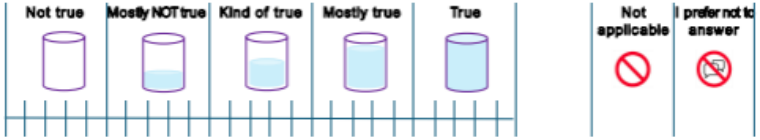
7. I feel that others want my company.



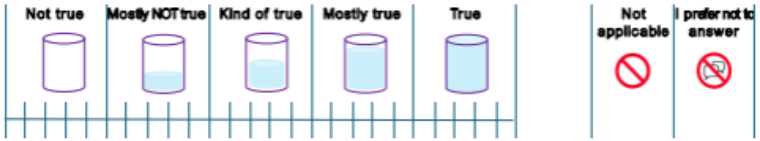
8. I like being on my own in safe spaces.



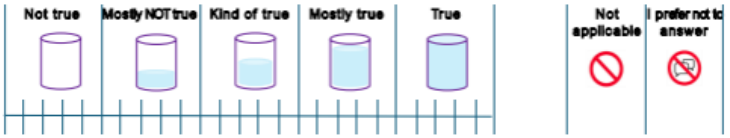
9. I have people in real life I like to be around.



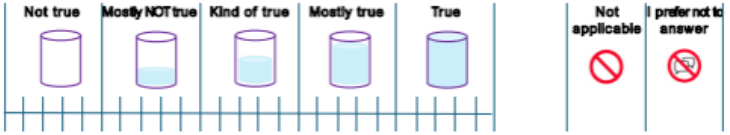
10. It is difficult to connect with people in busy environments.



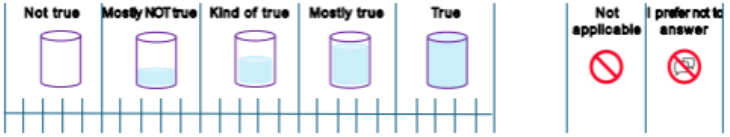
11. I like being with people I know.



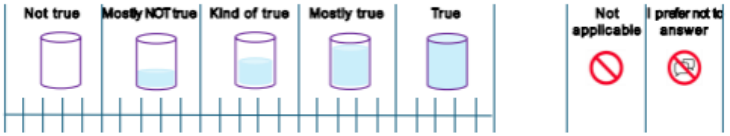
12. I have people who are happy to listen to me.



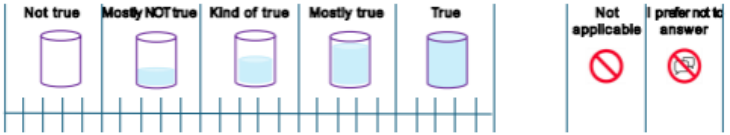
13. I find it difficult to be social.



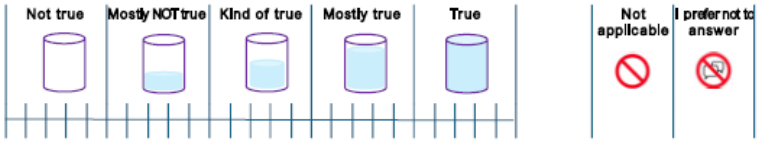
14. I have people who are interested in my wellbeing.



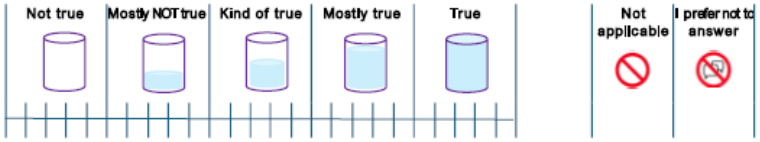
15. I prefer engaging with personal interests than being with other people.



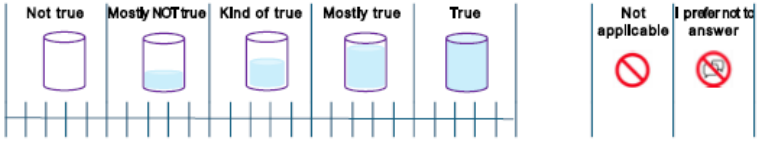
16. I feel emotionally low.



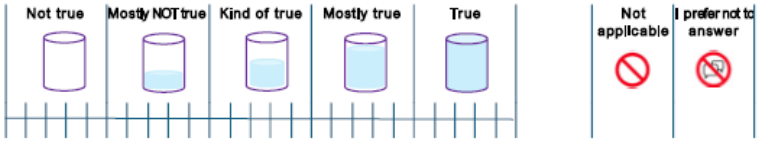
17. I know how to start conversations when I am in a group of people.



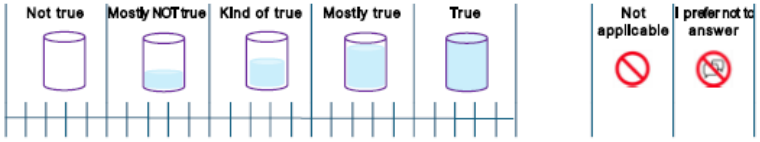
18. I have deep personal connections.



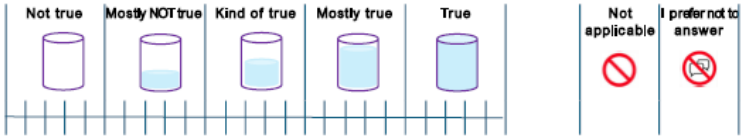
19. Good and positive sensory stimulation makes me feel less lonely.



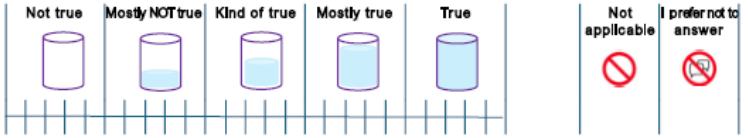
20. I find it difficult to get to know people out of school or college.



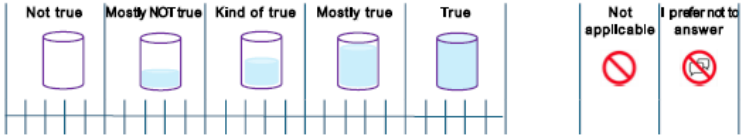
21. I feel like I fit in with other people.



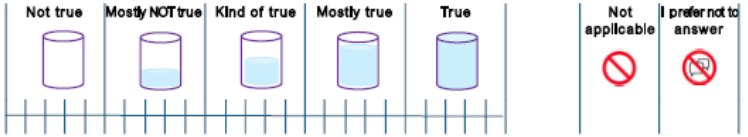
22. I feel I am accepted as I am.



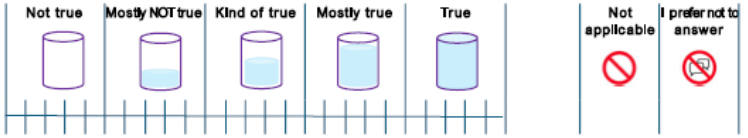
23. I have people I can talk to and have a good time with.



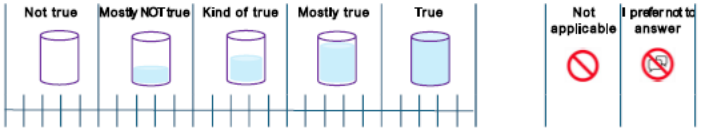
24. I don't want to be around people that often.



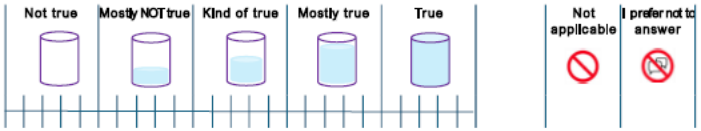
25. I feel overwhelmed when involved in social activities.



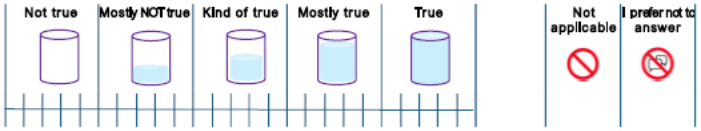
26. I would like to have more friends to interact with every day.



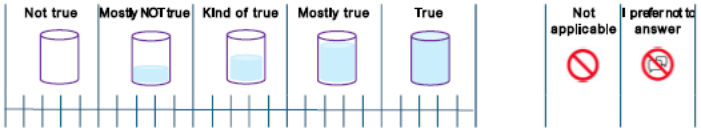
27. I have enough people in real life who make me feel good about myself.



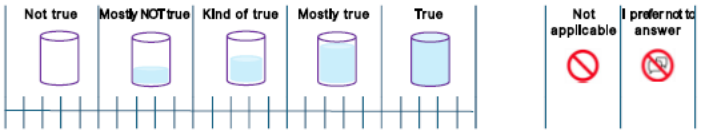
28. Being around people I know is enough for me not to feel lonely.



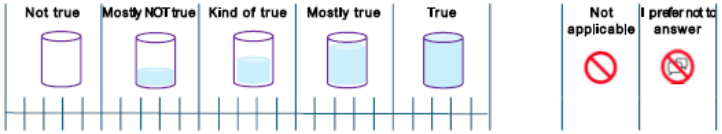
29. I am happy with the number of friends I have at the moment.



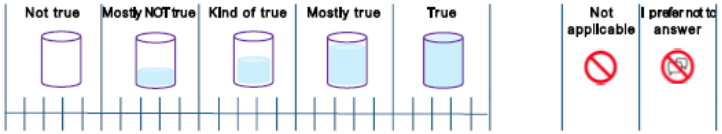
30. I can be myself around people I know.



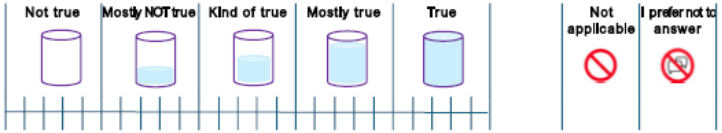
31. I feel there are other people like me.



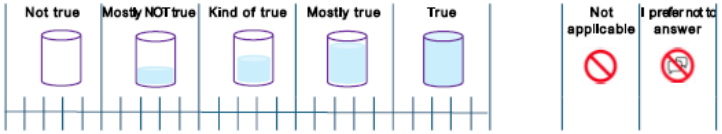
32. I have people in real life who I feel comfortable with.



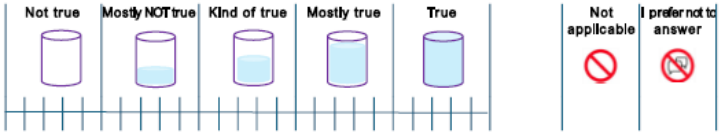
33. I feel less lonely when I connect to fictional characters (In movies , books, series, etc.)



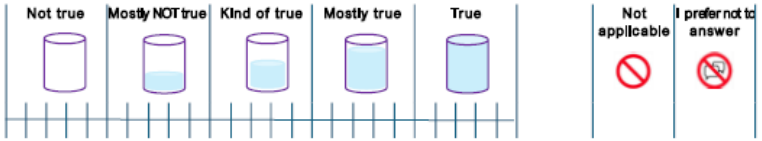
34. I prefer online interactions.



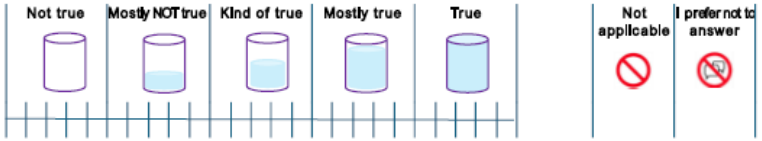
35. I can make new friends without help from adults or other friends.



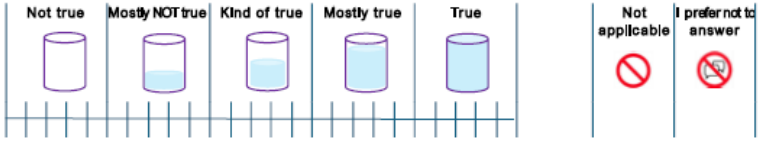
36. I have people who can give me emotional support.



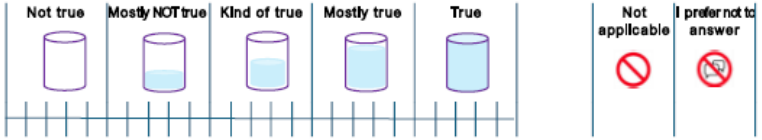
37. I feel connected to someone when we have the same interests.



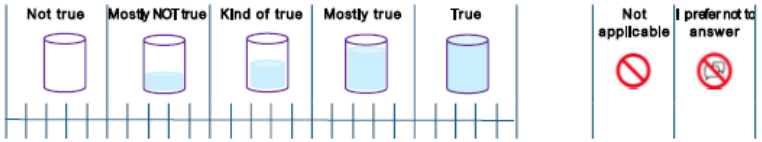
38. I have places where I can be myself.



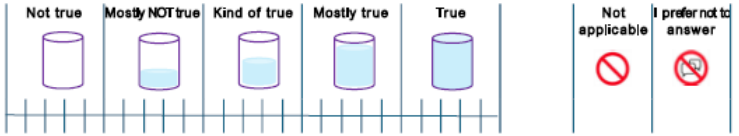
39. I have pets that are like friends.



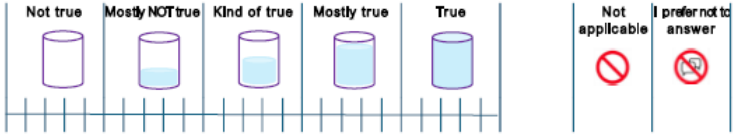
40. I feel I can communicate well with people.



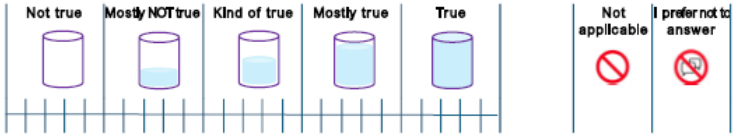
41. I find it difficult to connect with people who are the same age as I am.



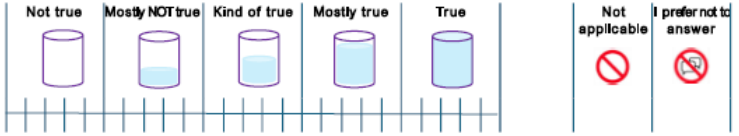
42. I prefer face-to-face connections.



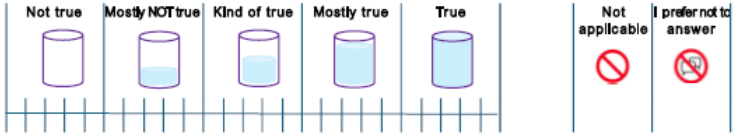
43. I feel alone amongst people I know. (e.g., friends, family, and other people I see daily).



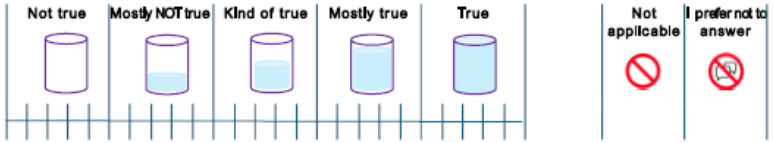
44. I feel I have to hide my true self most of the time.



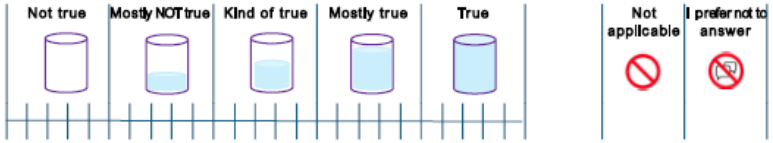
45. I have important objects that help when I feel lonely.



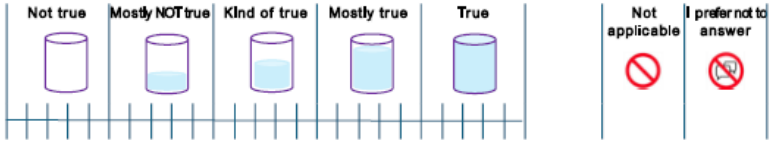
46. I know people in real life who understand me.



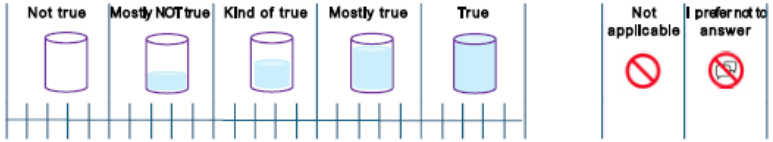
47. I have people in real life who I feel emotionally close to.



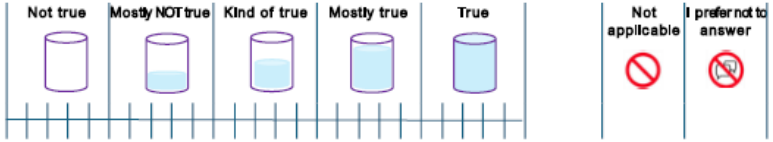
48. I am liked by people who are important to me in real life.



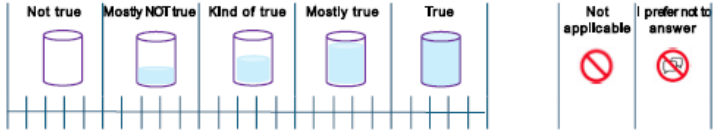
49. I feel I am included by people who are my age.



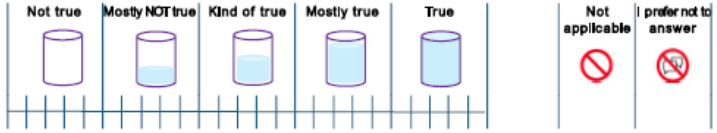
50. I feel judged by other people.



51. I feel happy when doing activities by myself.



52. Being alone is important to me.



Appendix L

Third Version of the ELSA

ELSA

Experiences of Loneliness – Scale for Autistic Young People

Why are you doing this?
We are interested in understanding your experiences of loneliness and connection.

There are no right or wrong answers.

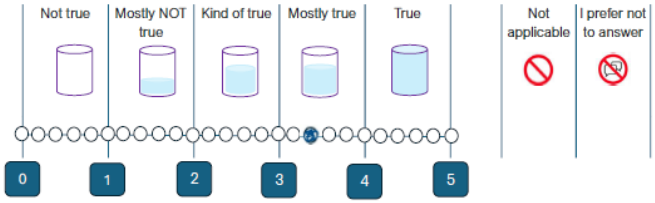
How to respond:

Please read each statement carefully and indicate how much it applies to you. Your answers should be based on how you are feeling today.

For each statement shade a circle on the line indicating how true the statement is to your experience. The start on the left is equivalent to not true (0) and the end on the right is equivalent to very true (5).

For example:

I enjoy talking to my friends face-to-face.



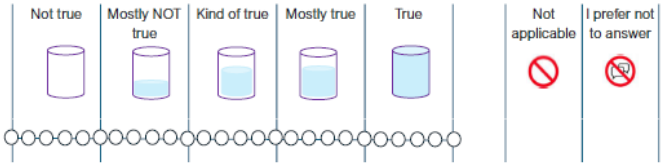
If a question does not apply to you, circle "not applicable".

If you prefer not to answer a question, circle "I prefer not to answer".

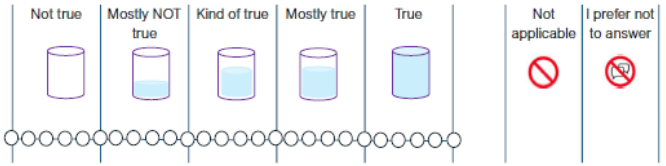
The grey boxes at the end of the page are a space for any reflections, comments, doodles or drawings you might want to add.

Your answers are confidential.

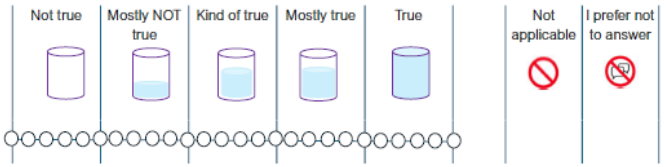
1. I have people I can talk to about things that bother me.



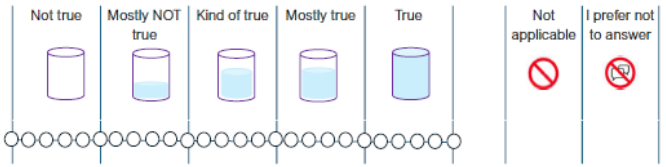
2. I feel lonely.



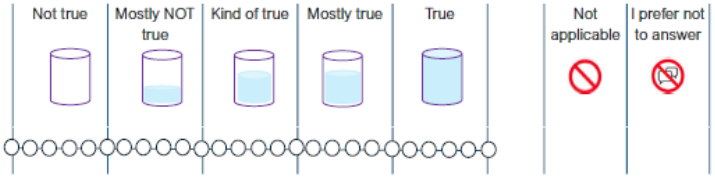
3. I have people who care about me.



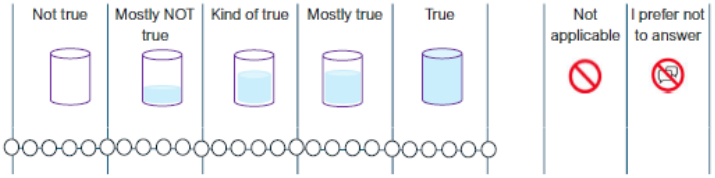
4. I feel I have to hide my true self most of the time.



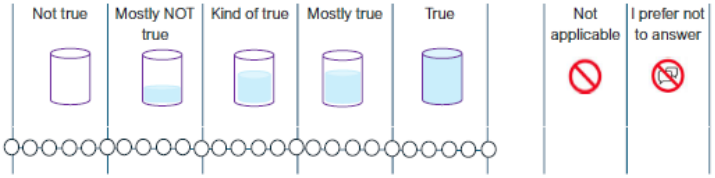
5. I have people I can do everyday activities with (e.g. having lunch, going to and from school/college, studying, playing videogames, going to clubs, etc.)



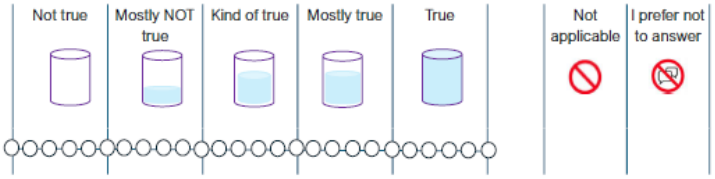
6. I feel different from what is expected of people my age.



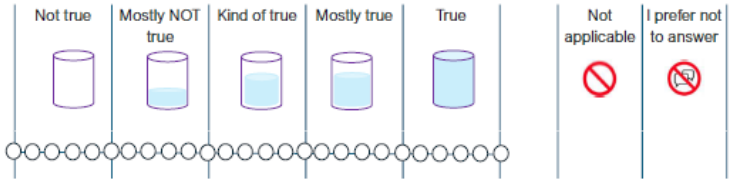
7. I have enough people in real life who make me feel good about myself.



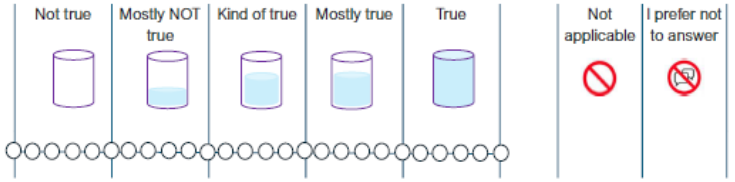
8. I feel less lonely when I connect to fictional characters (in movies , books, TV shows, games, etc.)



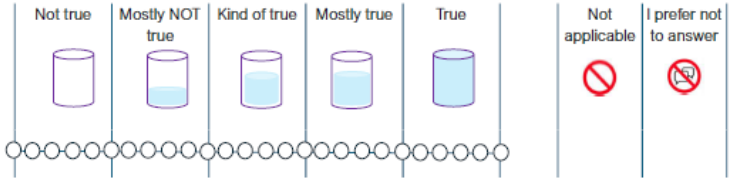
9. I have people in real life I like to be around.



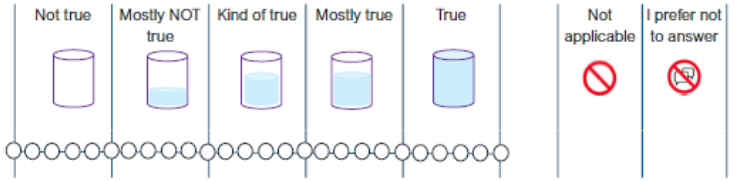
10. It is difficult to connect with people in busy environments.



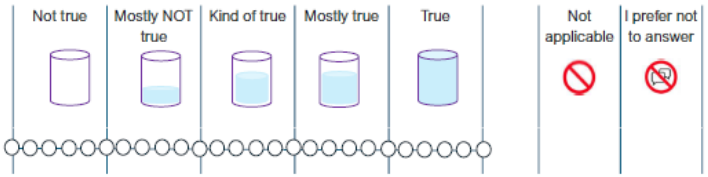
11. I have important objects that help when I feel lonely.



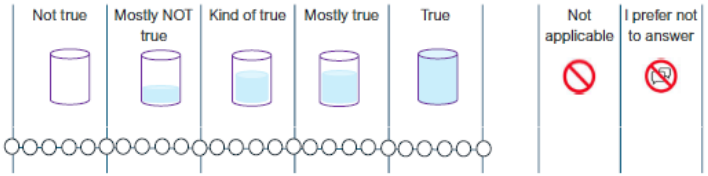
12. I have people who are there to listen to me.



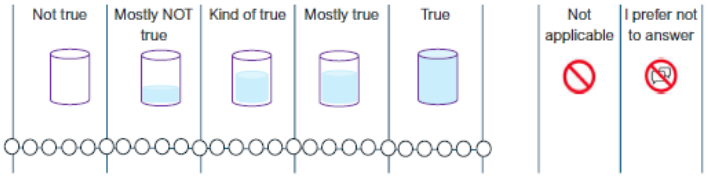
13. I find it difficult to be social.



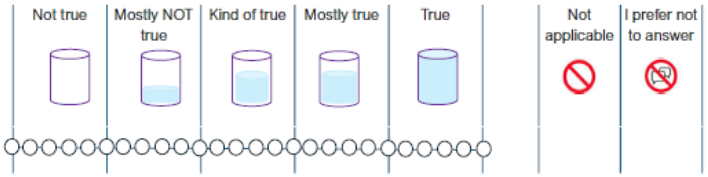
14. I have people who are interested in my wellbeing.



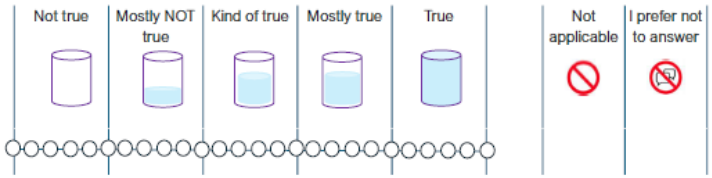
15. I have pets that are like friends.



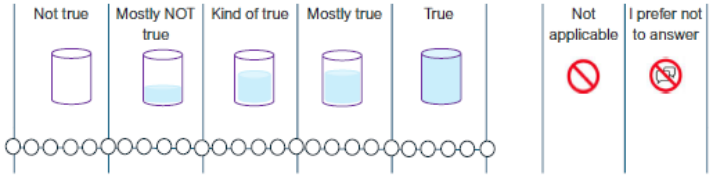
16. I feel emotionally low.



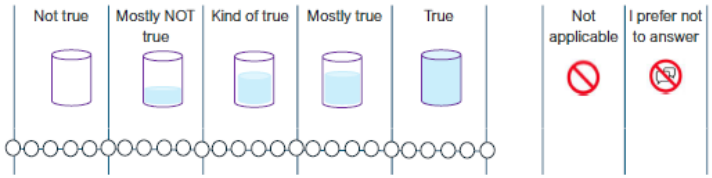
17. I can start conversations with people that are new to me.



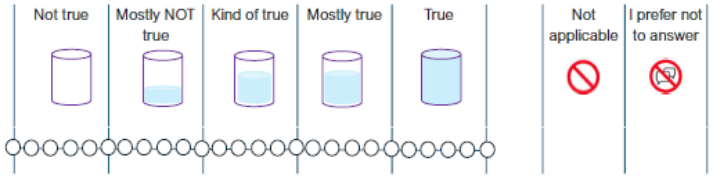
18. I have deep personal connections.



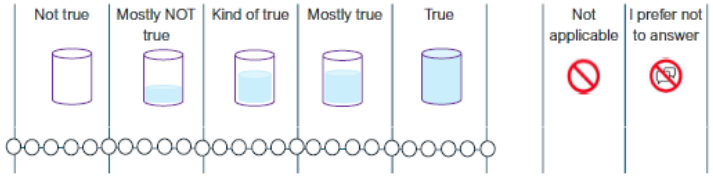
19. Being alone is important to me.



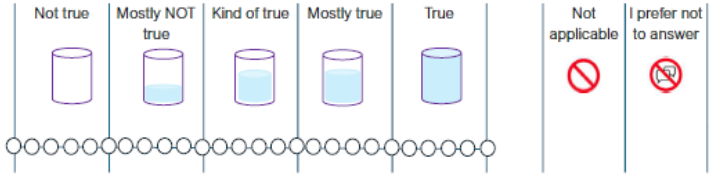
20. I find it difficult to get to know people out of school or college.



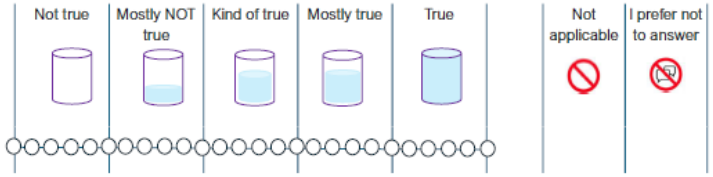
21. I feel like I fit in with other people.



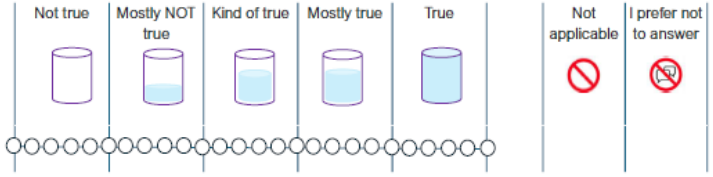
22. I feel I am accepted as I am.



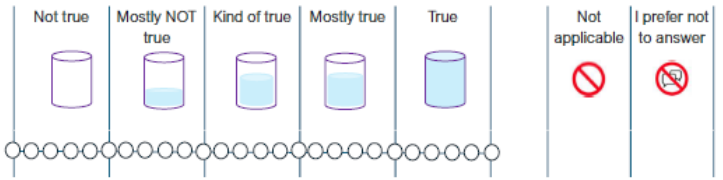
23. I have people I can talk to and have a good time with.



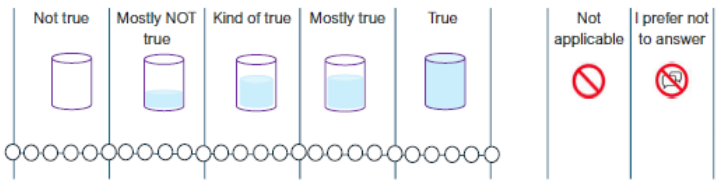
24. I don't want to be around people that often.



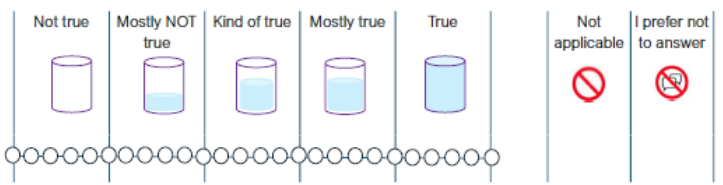
25. I feel overwhelmed when involved in social activities.



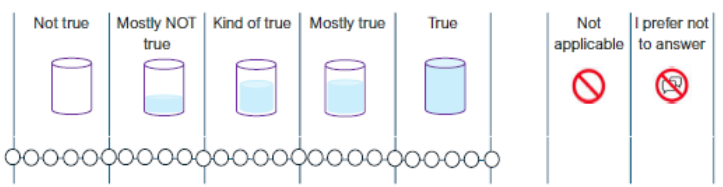
26. I would like to have more friends to interact with every day.



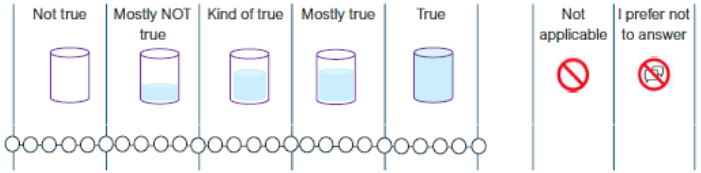
27. I feel that others want my company.



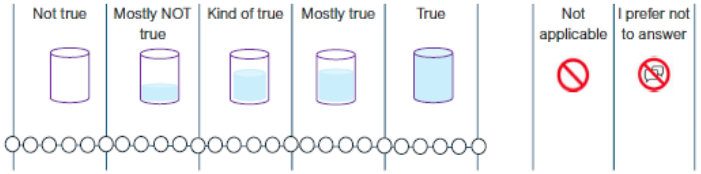
28. Being around people I know is enough for me not to feel lonely.



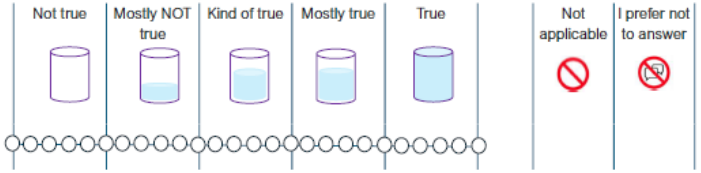
29. I am happy with the number of friends I have at the moment.



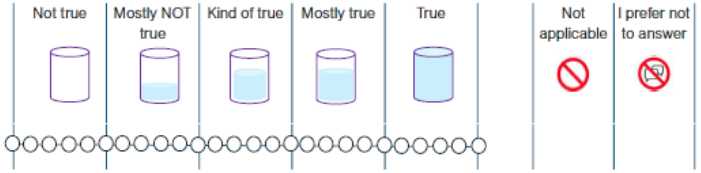
30. I can be myself around people I know.



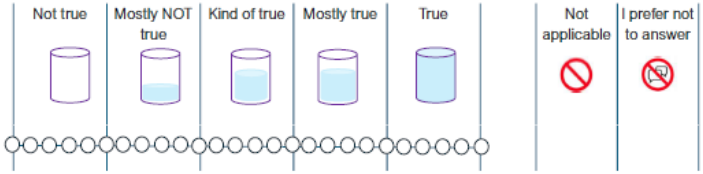
31. I feel there are other people like me.



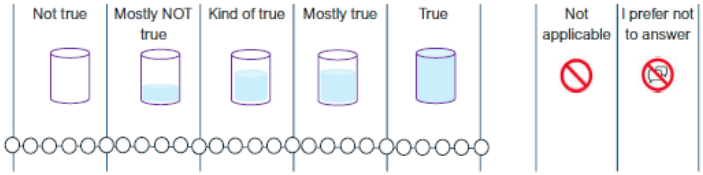
32. I have people in real life who I feel comfortable with.



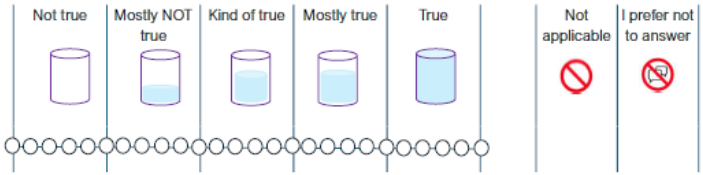
33. I like being on my own in safe spaces.



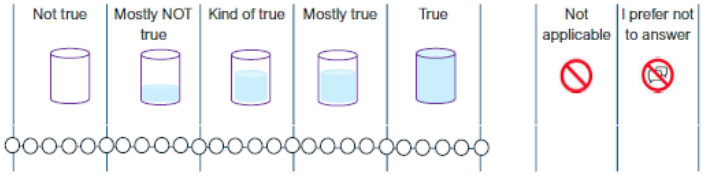
34. I prefer online interactions (e.g., texting, gaming, social media, video calling, etc.).



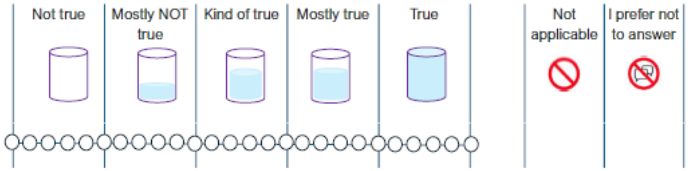
35. I can make new friends without help from adults or other friends.



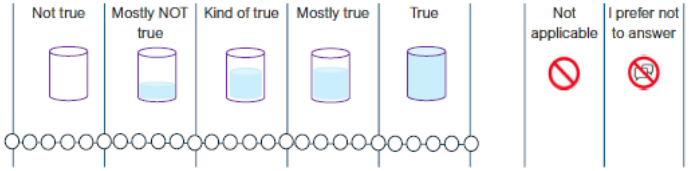
36. I have people who can give me emotional support.



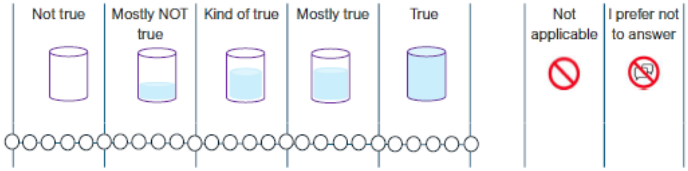
37. I feel connected to someone when we have the same interests.



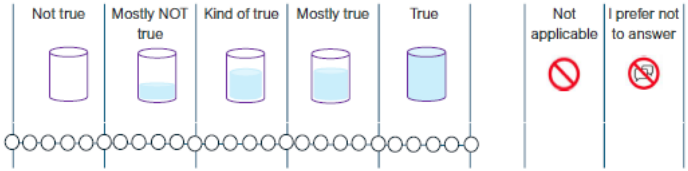
38. I have places where I can be myself.



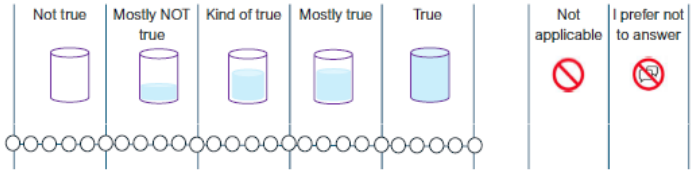
39. I prefer engaging with personal interests than being with other people.



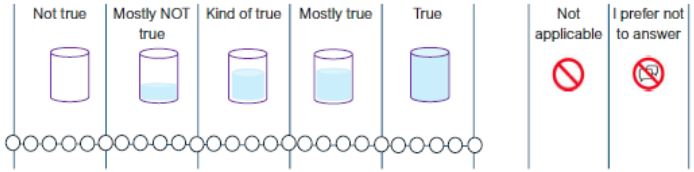
40. I feel I can communicate well with people.



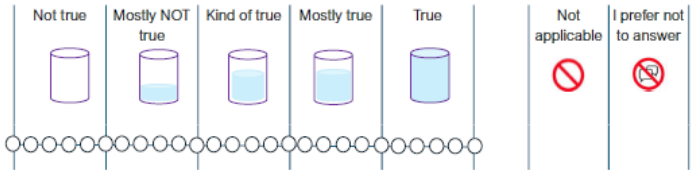
41. I find it difficult to connect with people who are the same age as I am.



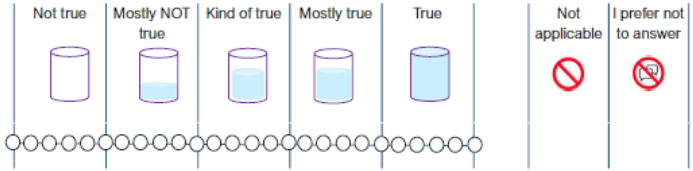
42. I prefer face-to-face connections.



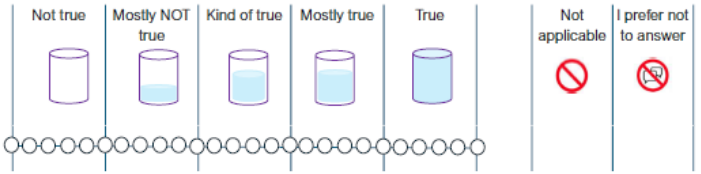
43. I feel alone amongst people I know. (e.g., friends, family, and other people I see daily).



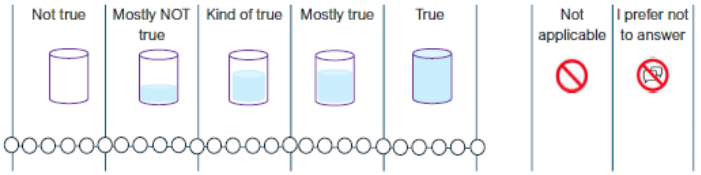
44. I feel misunderstood.



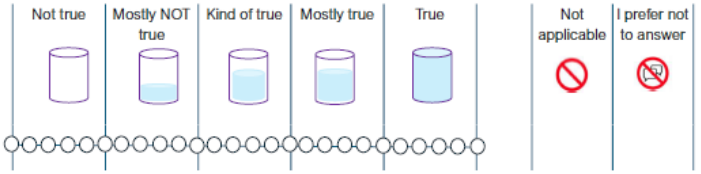
45. I like being with people I am familiar with.



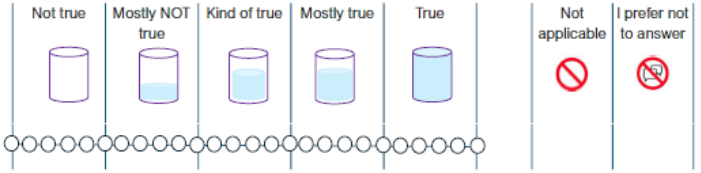
46. I know people in real life who understand me.



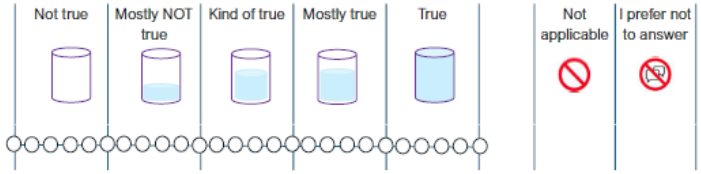
47. I have people in real life who I feel emotionally close to.



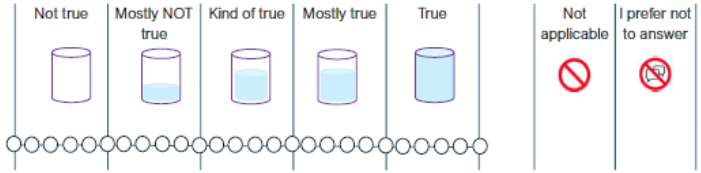
48. I am liked by people who are important to me in real life (e.g., friends, family members, etc.)



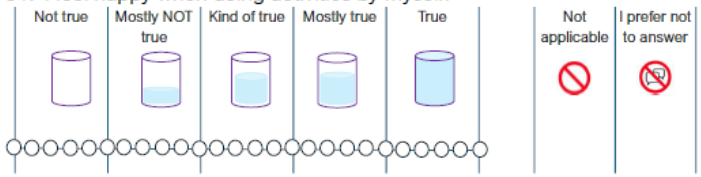
49. I feel I am included by people who are my age.



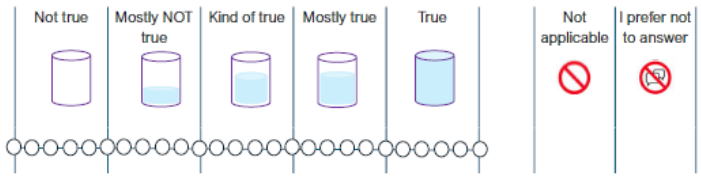
50. I feel judged by other people.



51. I feel happy when doing activities by myself.



52. Good and positive sensory stimulation makes me feel less lonely (e.g., cuddling a soft toy, using a weighted blanket, being in a darkened room, listening to soothing sounds, etc.).



Appendix M

Final Version of the ELSA

ELSA

Experiences of Loneliness – Scale for Autistic Young People

Why are you doing this?
We are interested in understanding your experiences of loneliness and connection.

There are no right or wrong answers.

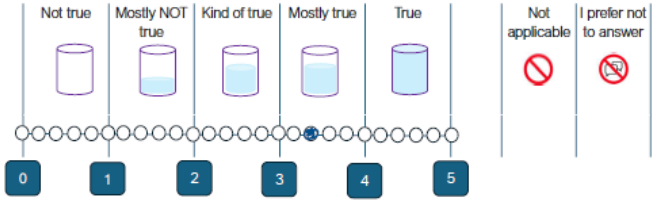
How to respond:

Please read each statement carefully and indicate how much it applies to you. Your answers should be based on how you are feeling today.

For each statement shade a circle on the line indicating how true the statement is to your experience. The start on the left is equivalent to not true (0) and the end on the right is equivalent to very true (5).

For example:

I enjoy talking to my friends face-to-face.



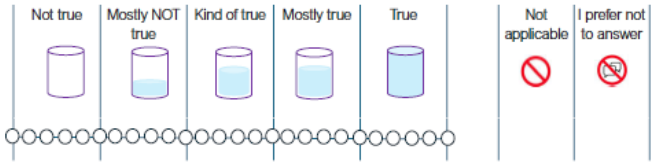
If a question does not apply to you, circle "not applicable".

If you prefer not to answer a question, circle "I prefer not to answer".

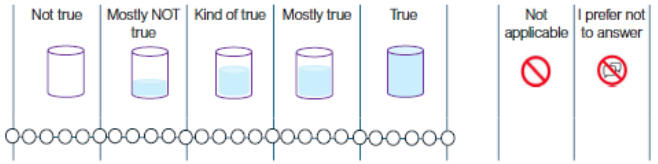
The boxes at the end of the page are a space for any reflections, comments, doodles or drawings you might want to add.

Your answers are confidential.

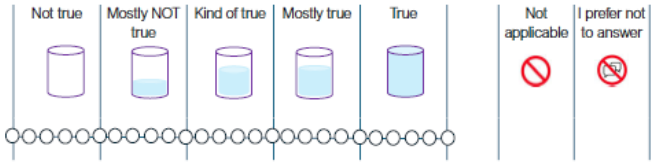
1. I have people I can talk to about things that bother me.



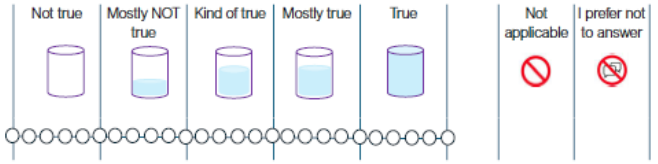
2. I feel lonely.



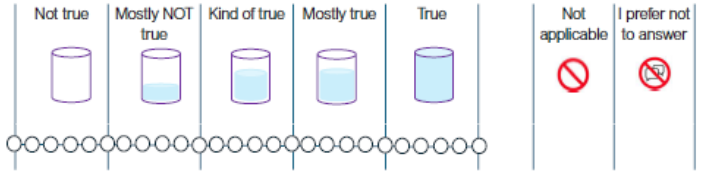
3. I have people who can give me emotional support.



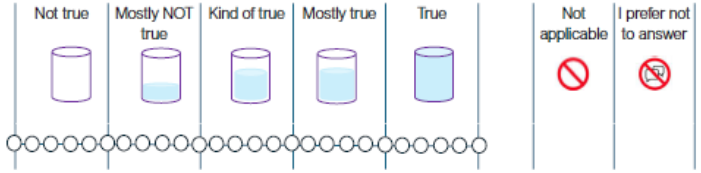
4. I feel I have to hide my true self most of the time.



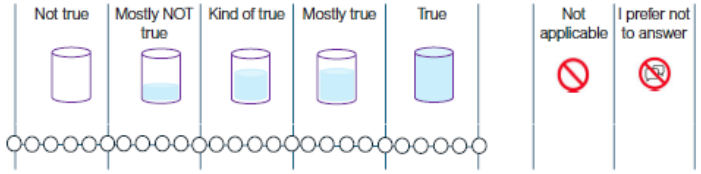
5. I have people I can do everyday activities with (e.g. having lunch, going to and from school/college, studying, playing videogames, going to clubs, etc.)



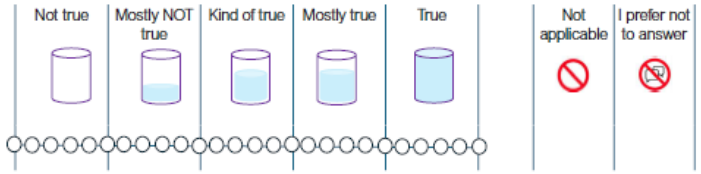
6. I feel different from what is expected of people my age.



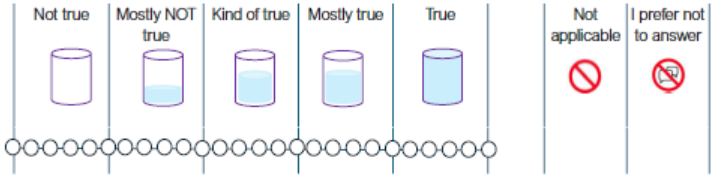
7. I have enough people in real life who make me feel good about myself.



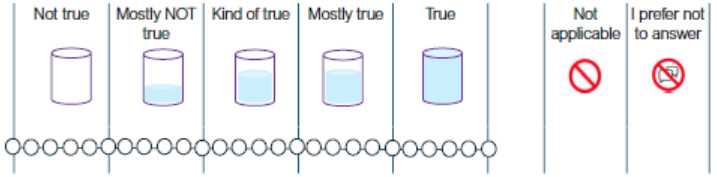
8. I feel less lonely when I connect to fictional characters (in movies , books, TV shows, games, etc.)



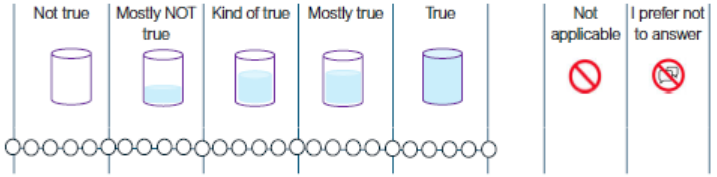
9. I have people in real life I like to be around.



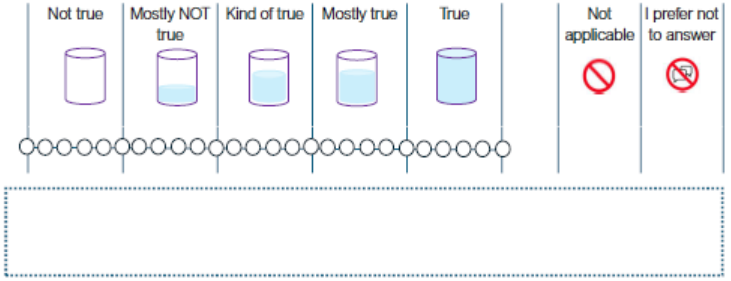
10. It is difficult to connect with people in busy environments.



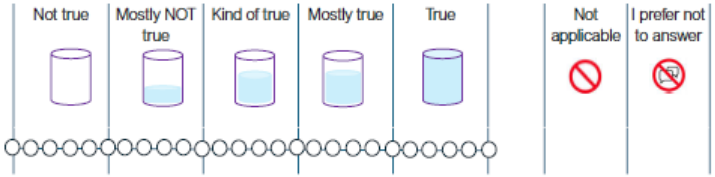
11. I have important objects that help when I feel lonely.



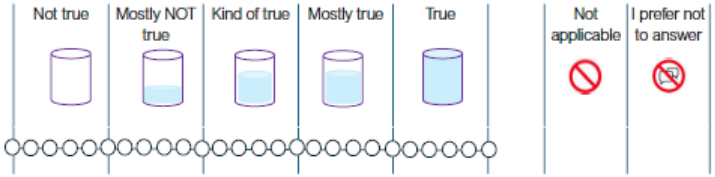
12. I have people who are there to listen to me.



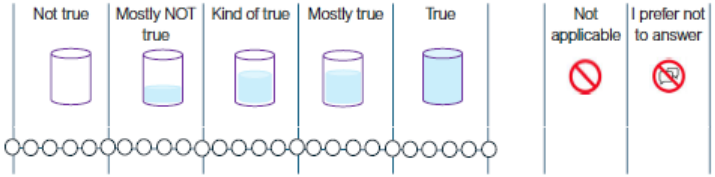
13. I find it difficult to be social.



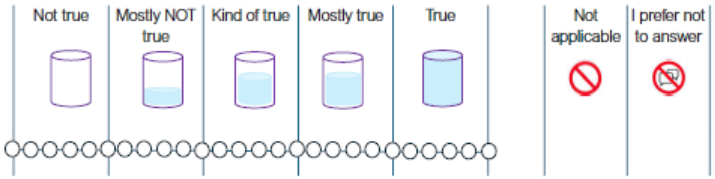
14. I have people who are interested in my wellbeing.



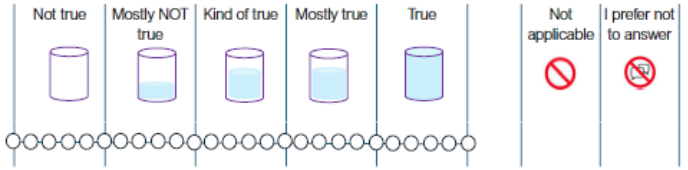
15. I have pets that are like friends.



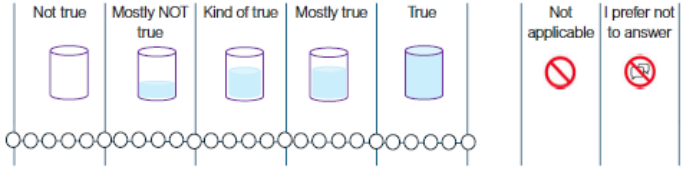
16. I feel emotionally low. (e.g. I feel down, sad, etc.)



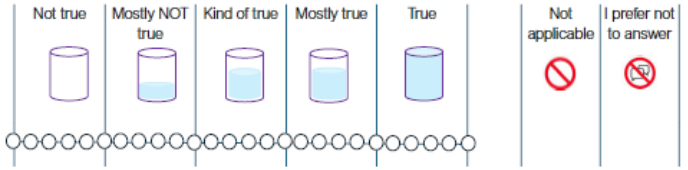
17. I can start conversations with people that are new to me.



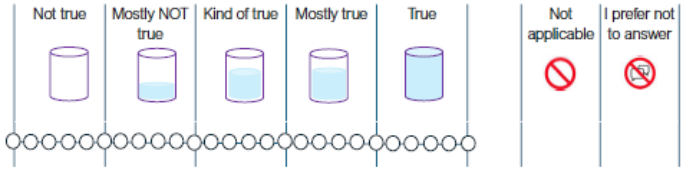
18. Good and positive sensory stimulation makes me feel less lonely (e.g., cuddling a soft toy, using a weighted blanket, being in a darkened room, listening to soothing sounds, etc.).



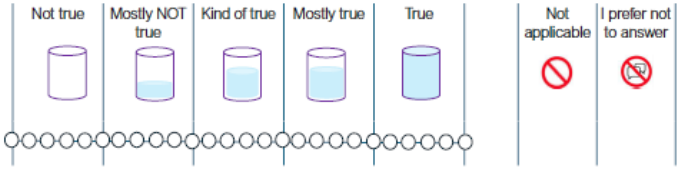
19. Being alone is important to me.



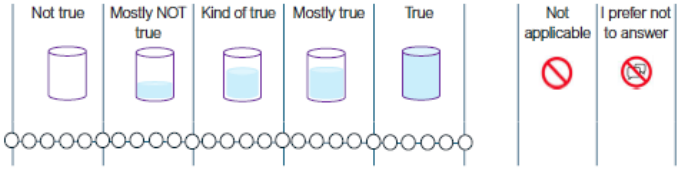
20. I find it difficult to get to know people out of school or college.



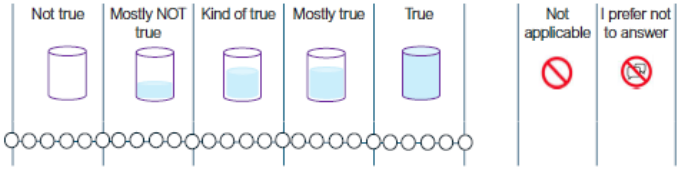
21. I feel like I fit in with other people.



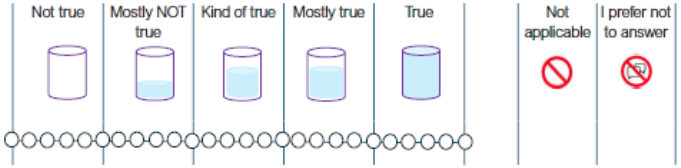
22. Overall, I feel I am accepted as I am.



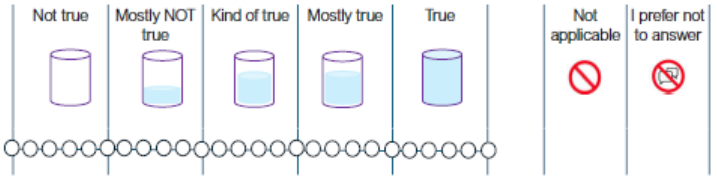
23. I am liked by people who are important to me in real life (e.g., friends, family members, etc.)



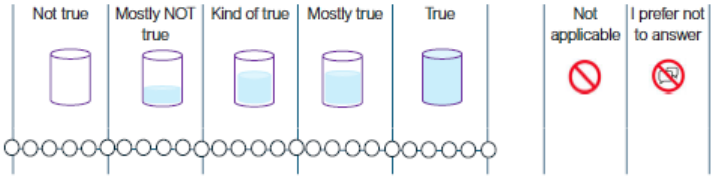
24. I don't want to be around people that often.



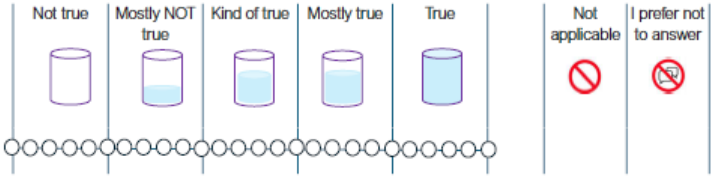
25. I feel overwhelmed when involved in social activities.



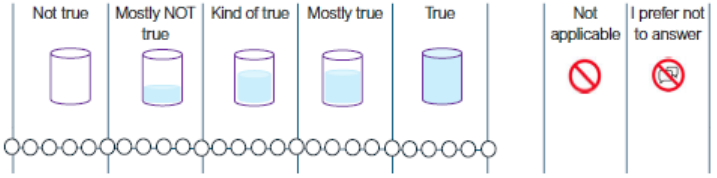
26. I would like to have more friends to interact with every day.



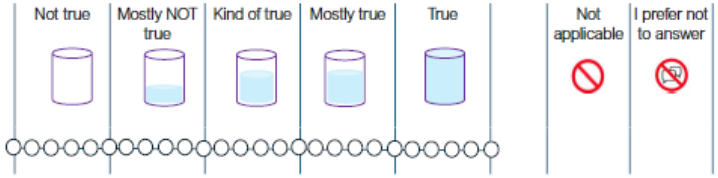
27. I feel that others want my company.



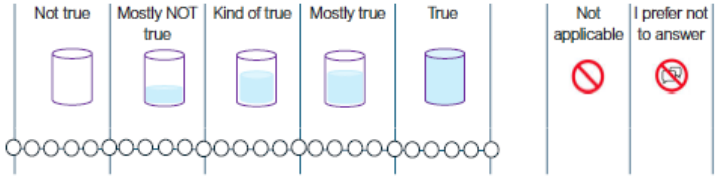
28. Being in the presence of people I know makes me feel less lonely.



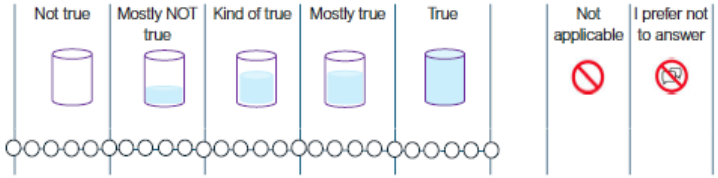
29. I am happy with the number of friends I have at the moment.



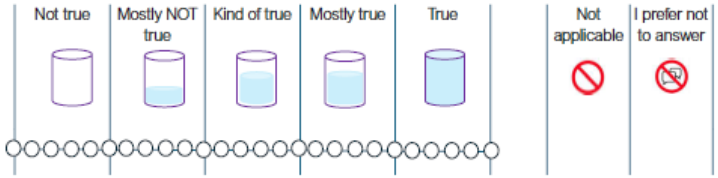
30. I can be myself around people I know.



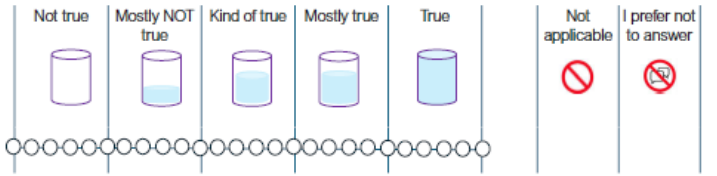
31. I feel there are other people like me.



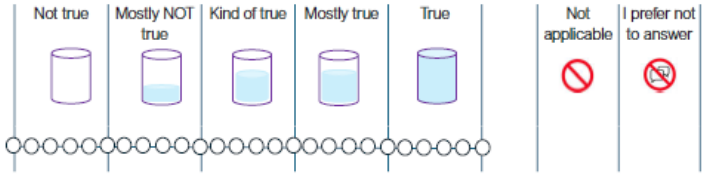
32. I have people in real life who I feel comfortable with.



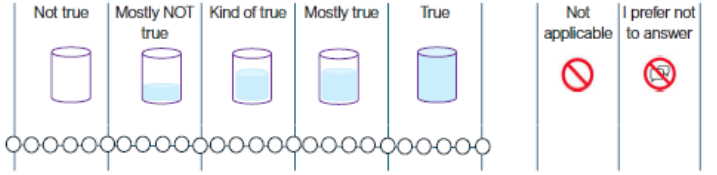
33. I like being on my own in safe spaces.



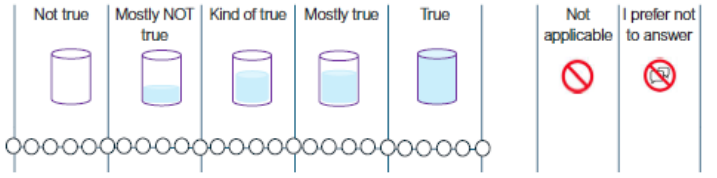
34. I prefer online interactions (e.g., texting, gaming, social media, video calling, etc.).



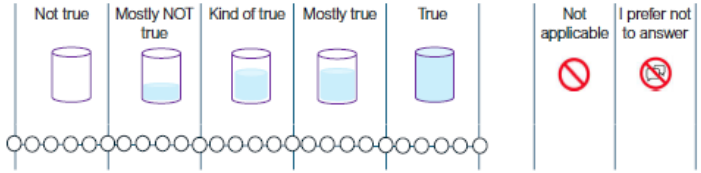
35. I can make new friends without help from adults or other friends.



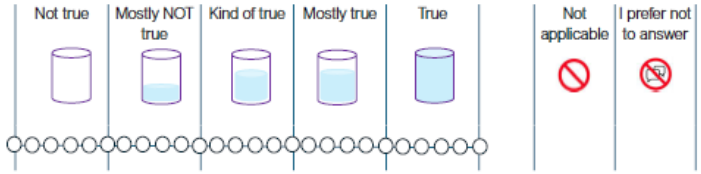
36. I have people who care about me.



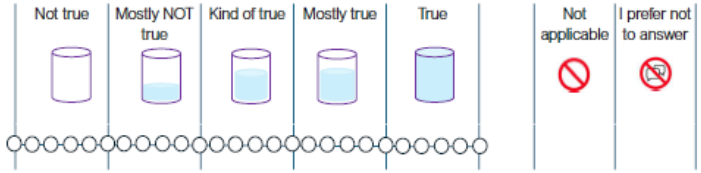
37. I feel connected to someone when we have the same interests.



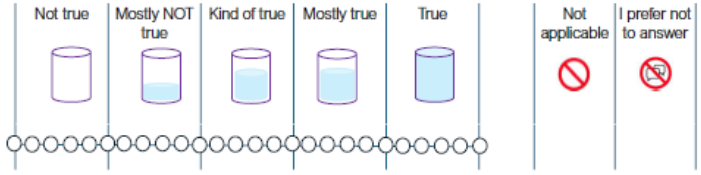
38. I have places where I can be myself.



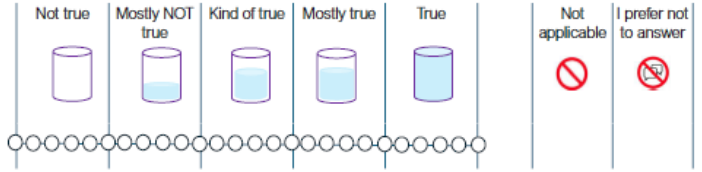
39. I prefer engaging with personal interests than being with other people.



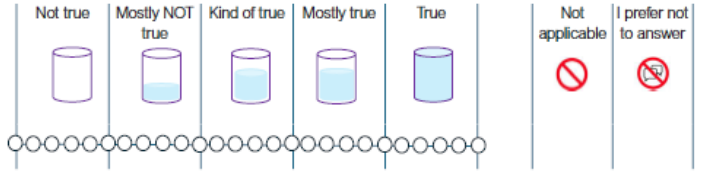
40. I feel I can communicate well with people.



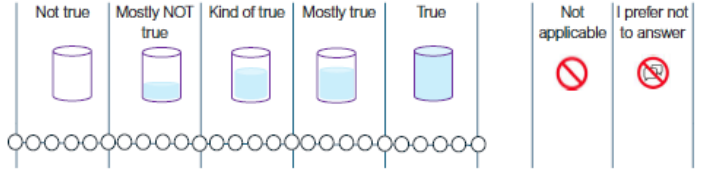
41. I find it difficult to connect with people who are the same age as I am.



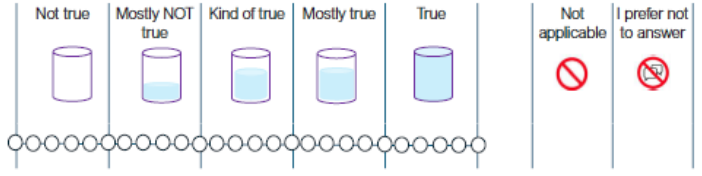
42. I prefer face-to-face connections.



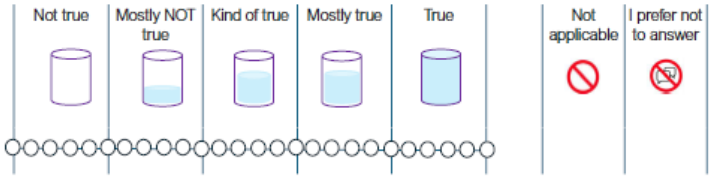
43. Overall, I feel lonely amongst people in my everyday life. (e.g. in school, college, work, etc)



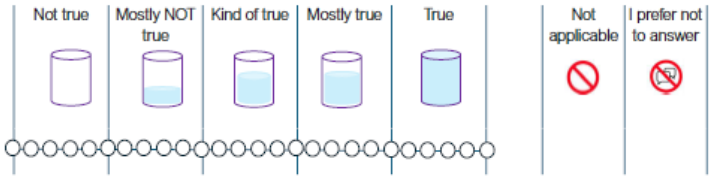
44. I feel misunderstood.



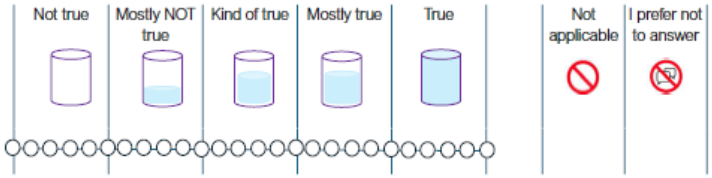
45. I like being with people I am familiar with.



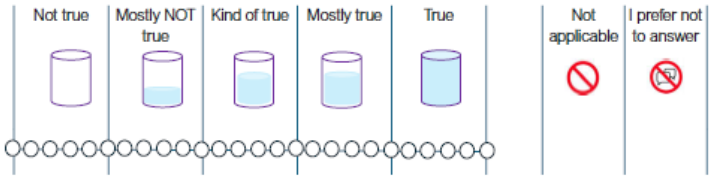
46. I know people in real life who understand me.



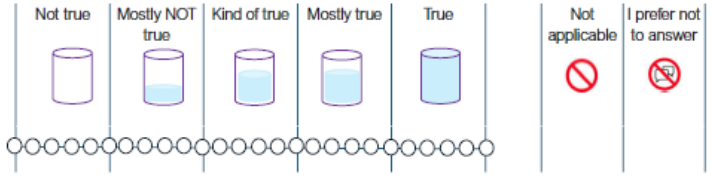
47. I have people in real life who I feel emotionally close to.



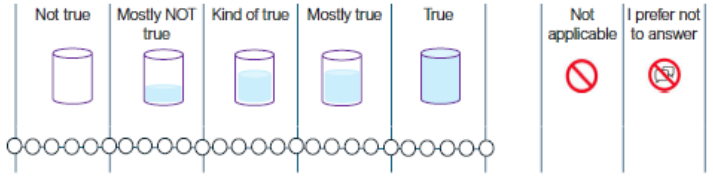
48. I have people I can talk to and have a good time with.



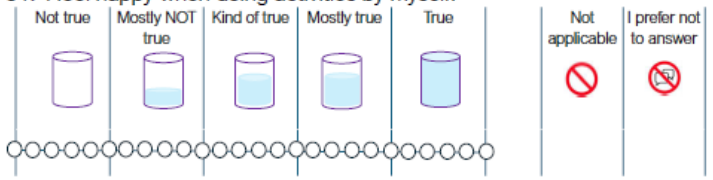
49. I feel I am included by people who are my age.



50. I feel judged by other people.



51. I feel happy when doing activities by myself.



52. I have deep personal connections.

