# RaY

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**Title**

A blog-based study of autistic adults' experiences of aloneness and connection and the interplay with wellbeing: corpus-based and thematic analyses

**Running Title**

Blog-based study of connection for autistic adults

**Abstract**

**Background:** Autistic adults appear to be more vulnerable to mental ill health, with loneliness being a variable associated with multiple outcomes of poorer wellbeing. However,

a description of meaningful social connection that is suitable for autistic adults is missing from this research, along with a missing understanding of the conditions that contribute to wellbeing.

**Methods:** In this study, autistic adults' experiences of connectedness and aloneness were systematically searched for within data collected from blogs. This contributed a creative method to hear the viewpoint of autistic adults. Corpus-based and thematic analyses explored the descriptions and contexts of relationships. A total of 16 autistic authors contributed views.

**Results:** Social connection was desired and was achieved through self-acceptance and rejecting deficit-based views of being autistic, and selectively choosing important relationships. Meaningful social connection changed over time, being more difficult to attain in childhood, and benefiting from self-learning and effortfully applying neuro-normative skills in social communication. Loneliness was only described alongside other causes of unhappiness and was not associated with being autistic.

**Conclusions:** The findings offer some explanation for the high estimates of both loneliness and mental ill health for autistic adults. We consider the implications for autistic individuals, clinicians, educators and researchers. We are also cautious not to imply that these views reflect all autistic people. The findings suggest that improvements are needed in society in order to share communication differences and relationship expectations for autistic individuals to be accepted and valued.

**Community Brief**

"Why is this an important issue?"

Autistic adults appear to be vulnerable to mental ill health, though this is often misunderstood. Being lonely, or dissatisfied with social relationships, has been linked to poorer wellbeing. However, most research uses questionnaires to assess loneliness, which make assumptions that need updating for autistic adults. For example, having fewer friends does not necessarily mean feeling lonely. We are also missing an understanding of what contexts make autistic people feel alone or connected.

"What was the purpose of this study?"

The purpose of this study was to hear the experiences of aloneness and social connectedness as described personally by autistic adults. We chose to use data from online blogs because the topics and descriptions were chosen through personal motivation of the authors and minimise assumptions made by researchers.

"What did the researchers do?"

We created a dataset of descriptions of social connectedness from the top trending blogs written by autistic authors. We used systematic search methods to do this. We chose 33 search terms that describe social connection and aloneness, as not to presume that autistic people are lonely, such as 'friendships' and 'belonging'. We analysed the descriptions first using a computer programme to find patterns in language, including the most frequent descriptions. This is called corpus-based analysis. It was chosen to reduce the bias that researchers can introduce when they look for themes in what people talk about. Second, we used a method called thematic analysis to explore the shared meanings in the descriptions,

which helped us to understand the contexts of relationships. We collected views from 16 autistic authors.

"What were the results of the study?"

The results showed that the blog authors desired social connection and had meaningful relationships. This was achieved through self-acceptance and self-compassion. Authors said they learned about themselves over time. They learnt social skills that they thought were expected by non-autistic peers. They also rejected the view that being autistic was a negative thing. Loneliness was described only when people had other things making them unhappy, such as anxiety or depression, and was not associated with being autistic more generally.

"What do these findings add to what was already known?"

Unhappiness with social relationships seems to occur in certain circumstances, which change over time. Importantly, these autistic authors said they felt connected when they had a positive identity, were understood by the people important to them and were able to make choices about how to invest in relationships.

"What are potential weaknesses in the study?"

We only heard from a small sample of autistic people, likely those with good internet skills who were interested in social media. This might be a group of people who are motivated to connect with other people. Also, we couldn't follow-up on the meanings of what was written because we had no interaction with participants.

"How will these findings help autistic adults now or in the future?"

Within healthcare, there seems to be a risk of misunderstanding autistic clients when practitioners use questionnaires to assess wellbeing or loneliness, when the questionnaires are not created for autistic people. We recommend not assuming loneliness, but instead, asking

whether feeling lonely occurs under certain circumstances. There is more for clinicians and researchers and society to do to share the responsibility for social communication differences.

**Background**

Autism is mostly represented as a neurodevelopmental disorder, as defined by major diagnostic frameworks.[1,2] Therefore, in order to receive a diagnosis and associated support, autistic individuals need to demonstrate lifelong difficulties with social communication and social interaction across multiple contexts, restricted, repetitive patterns of behaviour, and, sometimes, sensory processing sensitivities. However, there is a significant and much-needed paradigmatic shift happening currently, which places greater emphasis on the lived experiences of autistic people,[3,4] and this is urging researchers to improve the collective understanding of experiences that are too-often presumed to be disordered. One priority topic is the wellbeing of autistic adults and the associated provision of support,[5] with wellbeing referring to a personally-defined state of feeling well, with manageable stresses, and being able to live to one's own potential.[6] There are strikingly high estimates of mental ill health co-occurrence with autism diagnosis, with mental health diagnoses such as depression and anxiety being more prevalent for autistic individuals than for the general population.[7] Over their lifetime, over 70% of autistic individuals are reported to have a mental health disorder.[8] There are additional concerns alongside high estimates of mental health disorder diagnoses, including anticipated lower self-esteem and higher suicidality for autistic adults.[8-10] Loneliness is suggested to be a contributing factor to reduced wellbeing, which is in need of further exploration.[11-14]

Loneliness is understood to be a negative feeling of unhappiness due to lack of social connections.[15] In some definitions of loneliness, 'emotional loneliness', or felt unhappiness in

relationships, is different from having fewer social connections,[16] though this important distinction is often missed, notably when loneliness is measured as a unitary construct. Aloneness, or lack of social connection, and loneliness are, therefore, two distinct concepts, each with their own interactions with wellbeing. Applied to the study of autism, the core diagnostic features of social communication difficulties, and the long-standing assumption that being autistic means preferring aloneness,[17,18] means there is an intuitive link between being autistic and being lonely. However, an exploration of meaningful connectedness, or its absence, for autistic people is only just emerging. Social connection is used in this study to mean a subjective experience of belonging and having valued closeness to others.

When questionnaires are used to assess loneliness and the connection with wellbeing, autistic adults report being moderately lonely.[12] In a recent systematic review, autistic adults were shown to report higher scores on measures of loneliness than a comparison group of non-autistic adults.[19] Loneliness ratings then associate with negative self-esteem, anxiety, depression, self-harm behaviours and suicidal ideation.[12-14] Autistic individuals report having fewer friendships and reduced quality of life specifically in relation to social relationships.[20] However, the use of such scales misses the context and the meanings of aloneness or connection, such as the interplay between characteristics of being autistic, having fewer social relationships and emotional distress, and the direction of these relationships. These study findings also fail to discern how static or inevitable these conclusions are. For example, friendships for autistic people are suggested to improve over time.[20] Use of scales that have not been designed for, or standardised with, autistic participants cause further confusion. For example, scale items such as, "no one really knows me well,"[21] may not equate to distress. Stating, "it is difficult for me to make friends," may not reflect unhappiness with existing relationships. There have been similar critiques of standardised scales used to assess mood[22-

[24] and quality of life[25] for autistic participants, due to not knowing which scale items are meaningful, and whether scores are therefore misleading.

A more contextualised understanding of connection and being autistic would consider a definition of meaningful relationships, and broader factors such as the implications of the high efforts often made by autistic adults to achieve normative social relationships, including camouflaging or masking to reflect 'acceptable' ways of behaving.[26] This is notably true for those with less stereotypical autistic 'symptoms', as seen in the literature, when women or those assigned female at birth receive a diagnosis of autism, or when individuals receive a diagnosis of autism later in adulthood, when there has been personal confusion around autistic identity.[27-29] Qualitative explorations of loneliness, so far, have discussed the interplays between societal expectations, social skill differences and past negative experiences of feeling different.[30] Wider research literature also considers factors of bullying and the availability of support sources on satisfaction with relationships, which provides a more helpful context for understanding loneliness.[31]

Importantly, the predominant understanding of loneliness and its implications has been only minimally-informed by autistic viewpoints. Causton-Theoharis et al.[17] explored loneliness through published autobiographical narratives of seven autistic adults. Friendships were desired and were a protective factor against poor mental health, but difficulties maintaining friendships included problems with reaching shared communication and predicting other people's intentions. Ee et al.[30] analysed qualitative survey data from autistic adults, who said there is a difference between being alone and being lonely. They reported widely variable experiences of social relationships. This emerging qualitative research demonstrates the need for improved understanding of the multifaceted interactions between being autistic and feeling satisfied with connectedness.

Research is needed into autistic people's life experiences, their perceptions of their own wellbeing and their coping strategies.[4,32,33] This would align with ways of understanding autism as neurodivergence,[34] where autistic individuals are recognised as having strengths and widely variable expressions of autistic traits.[4] Importantly, autistic individuals should set the topic of conversation and the means of contributing research data, through creative methods.[35,36] Difficulties can then be more fully understood within a context, of how a person interacts with the environment that they inhabit.[37]

This study sought understanding from autistic adults' own perspectives of their experiences of aloneness or social connection, and the interplay with wellbeing. While this research sought to better understand 'loneliness', the term social connection is used from this point forward to frame the research question and the search strategy as to avoid deficit-based assumptions.

This study analyses blog posts written by autistic adults. Studying blogs demonstrates the use of inclusive research practices,[5,36] which give personal voice in a meaningful way to autistic participants. The appeal of blogging can be particularly attractive to some autistic individuals due the reduced demand on using normative social behaviours or responding to direct questions.[38] In contrast to other research methods, creative methods such as this reduce researcher influence.[35] This is particularly important given the potential to misunderstand and oppress neurodivergent voices,[39] which can happen when researchers design questions and research methods using understandings derived from outside of the autistic community.[33] Blogs offer an insider's point of view that is meaningful to the author at the time of writing, driven by personal motivation and using language and concepts of their own choosing.[40-43]

**Method**s

Design

Online blogs written by autistic adults formed the research data, which were systematically searched for personal descriptions of social connection, and were compiled to create a specialised corpus. Corpus-based analysis was used to uncover patterns in language use. Thematic analysis was then used to interpret these patterns.

Data Collection

Blogs are an electronic journal that allow authors to share personal experiences.[40-43]

The blogsite Actually Autistic was used to search for blogs. Blogs were defined as personally written electronic journals that were updated on a regular basis, written in line with the guidelines proposed by Willis:[44] blogs were only accessed if they did not require a password and were intended to educate others, thus were meant for public consumption. Authors were over the age of 18 and had a self-reported diagnosis of Autism Spectrum Disorder (ASD). Some authors may have had a formal diagnosis of autism or be self-diagnosed, which was not confirmed. Furthermore, blogs were first person accounts of one's own life events on any topic (excluding topics such as recipes), written in English, and were posted between July 2021 and October 2021.

The top 35 trending blogs were screened for inclusion. Together with the criteria for including blogs in the dataset, this was an attempt to present web-based data that could be considered credible, by sourcing blogs from a site with clear guidance of its purpose, with author information provided, and with the blogs being deemed up-to-date by user engagement.[45] Data were located using blog trawling. This refers to gathering data that relates specifically to the topic of study and then cutting and pasting this text into a descriptive offline file.[46] User traffic was reviewed as a quality check of the relevance of each

blog, requiring blogs to be visited more than one thousand times. 14 blogs were excluded for not meeting these criteria or for having missing information to allow screening. All content from the 21 included blogs was exported into a general corpus.[47]

Following guidance for systematic searching,[48] the general corpus was searched using key terms to identify text where social connection was discussed. Search terms were created from synonyms of loneliness and social connection, friendships and relationships. Terms were added from relevant research papers that discussed similar concepts.[11,49-51] Additionally, five randomly selected blogs were read in full to identify search terms reflecting idiosyncratic language use. Truncation was used to increase the return of relevant text. A total of 33 search terms were applied, as shown in Table 1.

A specialised corpus[47] was formed from the descriptions of social connection, including their fuller written descriptions; these ranged from a single sentence to multiple paragraphs. A member of the research group independently read the specialised corpus to ensure its relevance to the research question and the sensibility of each extract in isolation of the fuller blog. The specialised corpus consisted of accounts from 16 authors, who contributed to a total of 21 blogs. The specialised corpus consisted of 20 251 words, which is considered to be a reasonable corpus size allowing for meaningful results.[52]

*Data Analysis*

Corpus-based analysis

Corpus-based analysis is a quantitative analysis method used to explore large texts and to discover patterns of language use, such as the frequency of word use.[47] Qualitative analysis is then used to explain these patterns.

A software package, Wordsmith Tools,[53] was used to first create a keyword analysis, comparing the frequency of words used in the specialised corpus with a comparison text,

which is a comprehensive sample of written and spoken English, the British National Corpus (BNC).[54] Keywords were the words highest in frequency in the specialised corpus when accounting for routine language use. They were ordered by 'keyness' – which is the statistical probability of the frequency difference. This demonstrates the single words most representative of the dataset in terms of their frequency use.[55]

Collocates are the words that frequently appear next to the keywords, as neighbours, which begin to reveal language patterns. Collocates for each keyword were sorted by Mutual Information (MI) score, which is a statistic used to show the strength of association between the keywords and their neighbouring words. The MI score disregards high frequency grammar words or word pairs that routinely occur together in language use (such as "the" preceding keywords) and only shows neighbouring words that have strong and non-random relationships, thus are able to illustrate this study dataset.

Concordance lines for each keyword were then displayed. These are fuller excerpts of blog text that show the keywords in their original context.

Corpus-based analysis provided an objective analysis of the most frequent descriptions of social connection, identified with reduced researcher influence.

Thematic analysis

Shared meanings and experiences of social connection across blog authors were analysed using mostly inductive, codebook thematic analysis, following six, flexible stages.[56,57] The fuller text around each keyword formed the basis of the analysis, though the full specialised corpus was read repeatedly for familiarisation. Text that contained features of data relating to the research question was coded in a systematic way by three researchers who rotated their roles to increase the transparency of the process and reduce individual researcher bias.[58] Codebook thematic analysis allows the blog data, and familiarisation with the data, to inform

a coding framework, with an aim of this method being to increase the accuracy, or consistency, of the judgments of multiple researchers. Importantly, however, this method sits within a qualitative philosophy of telling the 'story' and creating meaning, with some researcher influence, rather than uncovering the 'truth'.[57] Codes can be described as the smallest unit of thematic analysis, allowing researchers to identify data that could potentially be of relevance to the overall research question. A codebook documented each code and exemplary quotes. Similar coded concepts were then grouped to generate potential themes of shared meaning across the entire data set, to create a map of the analysis. Themes are considered to be observable response patterns found woven throughout the specialised corpus, which have valuable meaning for understanding descriptions and contexts of social connection. The themes were named to tell the story of the analysis. Finally, extract examples were selected to relate the analysis to the research question and the literature and produce a report.

Ethical considerations

This study was approved by the York St John University ethics committee. All data was available in the public domain. Blog authors were not directly identified in the dataset to offer partial anonymity, though the quoted text would allow blogs to be found.[59] Guidelines for internet-mediated research informed these decisions.[60]

Considering the positionality of the researchers, one member of the author team identified as neurodivergent; three members identified as neurotypical.

**Results**

Corpus-based analysis

Keywords from the blog descriptions of social connection are shown in Table 2. Only content words are displayed: high frequency grammar words and those typical of blog data but not relevant to the research question were excluded (for example, "about" and "myself" are not displayed). 15 keywords are shown, informed by the strength of keyness thresholds used in previous literature.[61] The log-ratios show how common the keywords are when compared with the reference text, for example a ratio of 1 would mean the word was twice as common in the study data;[53] "social" was four times more common in the blog data than in the reference text, which is not surprising given the creation of the dataset, but shows relative frequencies within the dataset. Collocates, or neighbouring words, with a strong relationship to each keyword are also shown. A selection of concordance lines shows the keywords in their original context in Table 3.

Within the descriptions of social connection, being "autistic" was the most frequent description of identity, which was expected given the dataset, however, the prevalence of self-descriptions of being an "autistic student" illustrates the relevance of education settings for these authors. Other keywords that depicted identity were "allistic," "neurotypical," and "disabled." These were used within comparisons of the self with other people. The second most frequent keyword was "learned," which occurred most frequently alongside "skills." "Communication skills," "boundaries," and the "respect[ing]" of boundaries, also illustrated the most frequent content of this dataset. When "social" appeared in the dataset, the fuller excerpts shown in Table 3 indicate stressors and strains of social demands. "Trauma" appears in the keyword list, showing its relevance within the descriptions of social experiences. When discussing "relationships," choosing relationships and making efforts within relationships, alongside positive descriptions of relationships, are illustrated in the concordance line data. Finally, this analysis of the most frequent descriptions in this dataset highlights the presence of "friends" in the authors' lives.

Themes of shared meanings within the full dataset are presented next.

Thematic analysis

Two themes with accompanying subthemes are shown in Table 4 with example quotes. The themes are barriers to meaningful social connection and ways that autistic authors improved social connection.

*Theme 1: Barriers to meaningful social connection*

When discussing social connection, authors discussed reasons why differences from presumed or majority ways of relating had led to distress for them personally, and led to misunderstandings from others. Barriers to 'typical' social relationships included different communication, having an unclear autistic identity and learned withdrawal and aloneness.

Subtheme 1.1: Different communication

One recurrent reflection was that miscommunication was typical within social interactions, with blog authors describing social information as being subtle, indirect and unclear, and easily missed. Some authors described processing information more slowly and therefore missing their time to contribute within interactions. Another explanation for relationship difficulties was that the autistic authors omitted seemingly expected communications, which to them could seem empty or dishonest, such as hugging, making eye contact, speaking on the telephone or replying quickly to messages. This could be interpreted by others as them giving low importance or value to relationships that were actually meaningful to them, which was an error in interpretation on behalf of other people. Additionally, expectations to socialise in person and in real-time, in overwhelming environments, at parties or social gatherings, with layers of sounds and light, meant opportunities for social relationships were

reduced. Within the blog platform, the authors requested that expectations and boundaries within social interactions be voiced clearly, and they said this is not rudeness. Rather, clear expectations would remove a barrier that otherwise could cause repeated and damaging patterns in relationships. While it is inferred that miscommunications were being described from within interactions with non-autistic people, this information was not available in all accounts. The descriptions of difference may reflect more general personal communication differences.

Blog authors referred to myths that they themselves had assumed to be true, such as friendships being unachievable to autistic people, which they wanted to disprove.

Subtheme 1.2: Unclear autistic identity

When reflecting on their experiences of social connection, bloggers expressed how other people held expectations for them to be considered "normal" in society, or else "defective," (Blogs 2, 4, 5, 7, 9, 15, 16 and 21), when failing to "get it right" or behave "properly," (Blogs 4 and 14). They said they operated with reduced social energy or battery. "Fak[ing] it," "blend[ing] in," "masking," and "camouflaging," (Blogs 1, 5, 6, 14, 18, 20 and 21) were said to be expected behaviours in order to socialise, which they said they maintained for some amount of time, but which had a relational consequence. Making high personal effort to meet social expectations had an immense "toll," "drag," "force," and "strain," (Blogs 1, 3, 4, 5, 14 and 21) and contributed to identity confusion. For example, seeming "too 'weird' to be included in the friendships … too weird to be normal but not autistic enough to be autistic," (Blog 18). They held negative views about themselves, such as being a "bad friend," being "flaky," or "selfish," (Blogs 1 and 3). Identity confusion was discussed more specifically when authors identified as female and when they were labelled as high-functioning.

Being 'disabled' was a conflicting identity, experienced more specifically when job-seeking, when authors described being viewed as both too capable and too disabled simultaneously. Autistic disability was described as invisible and unrecognised, thus contributing to struggles in an environment where other people became positioned as able and ignorant. Repeated rejections from workplaces were described as being traumatic.

A range of descriptions in the blog data included being autistic and celebrated, looking non-autistic, and being negatively viewed as autistic when navigating social relationships, which helped to explain the different transient identities held.

Subtheme 1.3: Learned withdrawal and aloneness

For some, not being accommodated within social realms was described as a trauma: "trauma induced by being forced to function in a world I didn't comprehend, and couldn't conform to," (Blog 4). The anticipated requirement to make effort to perform within social situations caused people to be alert to situations that would be too-demanding, and to avoid situations that had previously felt were too demanding, which was likened to a way of coping with traumatic experiences. Emotional experiences were of shame or embarrassment for experiencing the world differently and for performing in social situations in ways that were different from what was expected, including being required to feign interest, to minimise the strain of sensory problems, to pay attention and to keep still. The bloggers described learned indifference towards other people and avoidance of other people.

There were two explicit mentions of loneliness in the dataset; for one author, loneliness was said to be caused by moving away from home when attending university. For another author, co-occurring anxiety and depression reduced their interactions with other people and friend-making potential. One blogger described the sadness of friendships ending despite caring about friendships, but not sadness at being alone. End to friendships was said to be a

consequence of expectations to accept social invitations, maintain continuous communication and reply to messages. Another blogger said, "while I am bad at making friends and don't have very many, I am not lonely. I don't feel like I'm lacking," (Blog 6). For some, aloneness was a positive coping strategy, and it offered time to enjoy fewer demands, to have a quieter mind and to process and make sense of the social interactions of the day.

*Theme 2: Improving connection*

In equal balance to barriers to reaching meaningful social connection, the blog authors discussed their ambitions for social relationships. Relationships were chosen, meaningful and built on self-acceptance, discussed as follows.

Subtheme 2.1: Self-acceptance

Self-acceptance assisted the authors in feeling socially connected to others. They described rejecting how they assumed society wanted them to behave as an unquestioned standard, "throwing out the NT 'rulebook'" and "not giving in," (Blog 4). Self-understanding translated into working out which social behaviours fit for them as an individual; which they were willing to perform, and which they weren't, with some trial and error from experimenting socially with others. Some authors said that self-acceptance led them to learn some people skills that they thought were expected by non-autistic peers, but this was informed by choice over when certain skills could be useful. It also led to some of the authors using both their limitations and their abilities to their advantage to develop meaningful relationships. Some bloggers described developing self-compassion, which could derive from making small victories and overcoming incremental challenges. Many bloggers mentioned self-acceptance improving their mental health, which resulted in more positive experiences of relationships.

Subtheme 2.2: Opportunities within education

Some bloggers described their student status at college or university as enabling them to develop their identity and find social connection, which was different from the discrimination and exclusion experienced in workplaces. The structure of education assisted them in finding social connections as they were exposed to a wide range of people, learning of people skills and navigating different types of situations. Higher education provided a context for learning self-advocacy, through interactions with academic staff, student support and disability services, mental health and wellbeing professionals, including, for example, agreeing conventions for communication in emails, chats and meetings. Self-advocacy skills were not formally taught.

Subtheme 2.3: Chosen relationships

Throughout the blogs, prominent themes were of valuing relationships, being selective over relationships and enhancing a sense of belonging through chosen relationships.

Most bloggers spoke indirectly of having best friends, good friends and close friends or partners. Support from friendships was described as "amazing," "reparative," and "deep[ly] supportive," (Blogs 4, 6 and 15). For some, friends were characterised as being those with whom they could be a "good sort of strange," (Blog 4). Some of the authors celebrated the discovery of people who were similar to them or who had similar values to them, which had assisted in relationships being more balanced. For example, some shared similarities with neurodivergent friends, or within an online community. This fostered a feeling of being part of a community. Some spoke of meaningful friendships with a pet. Authors were grateful for the relationships they had, frequently comparing their social relationships with others, such as those who had less support or critical friends and family.

The authors said, with friends, they say aloud things that are otherwise only implied by non-verbal communication, such as when it is time to leave a gathering. Some authors spoke of learning to communicate with their selected support networks.

Difficulties with social relationships were more apparent in childhood and teenage years, in part explained by the perceived expectations to socialise and felt pressures to either conform to the mainstream standards or to avoid social interactions.

**Discussion**

We sought to understand personal autistic experiences of social connection, described in naturalistic blog data, in order to better understand the interactions between connectedness or aloneness, and wellbeing. This was without an assumption that being autistic is associated with loneliness. The results show that unhappiness with social relationships is apparent under certain circumstances, which change over time.

Sadness within relationships was associated with a confused and, at times, defective identity – when the autistic authors compared themselves unfavourably with neuro-normative expectations. A lack of acceptance of self and lack of acceptance from others mirrored a deficit-based view of being autistic. This has previously been discussed as causing a separation between the individual and society.[4] Other research has demonstrated the impacts on self-perception when stigma becomes internalised and can lead to feelings of unworthiness.[62] Cooper et al.[63] demonstrated how self-esteem and wellbeing can be associated with a strong autistic identity, when individuals associate positive attributes with being autistic. Identity struggle has previously been described for those with less stereotypical autistic features, in the context of late diagnosis of autism or personal confusion

of an autistic identity for people assigned female at birth.[27-29] This study links these identity struggles with difficulty reaching satisfaction within social relationships.

Bloggers said that identity strain was more apparent for them in childhood. Previous qualitative research has also discussed the greater challenges faced by younger autistic people, suggested to relate to bullying and discrimination in schools.[63] Bullying and non-accepting environments have been associated with earlier school education,[31] as well as social situations at school being overwhelming and unavoidable, ironically creating a barrier to relationship forming,[64] as was described here. Difficulties with social connection in childhood are well documented, for example, autistic children have described feeling less security in their friendships.[65] This study suggests that there can be an accumulation of rejecting social experiences that carry forward into adulthood. This has been indicated in previous research that collected ratings of loneliness given by autistic adults over time, supplement by descriptions of past social experiences.[30] This narrative reflects our finding that past social experiences were described as traumatic for some autistic adults, contributing to withdrawal and aloneness. Therefore, into adulthood, autistic individuals are likely demonstrating their choices to be selective over how they form relationships, from carrying a burden of being marginalised.[39]

In our study, unhappiness with social relationships was associated with unquestioned expectations of how to interact with other people in order to build relationships, which reflected a neurotypical standard, and low shared understanding of what being autistic means. These tensions are well described within the neurodiversity paradigm.[4] The most prominent terms used in the descriptions of social connection, as revealed by the corpus-based analysis, suggested difference from allistic and neurotypical standards. The findings illustrate the efforts made by autistic people to learn expected communication skills, to negotiate

relationship boundaries and to negotiate autistic identity. The efforts made were often fuelled by autistic adults making comparisons with being neurotypical or being disabled.

Heasman and Gillespie[66] described the variety of ways of communicating in social interactions as intersubjectivity, where shared understanding is dependent upon shared conventions. They argue that neurotypical norms can limit the creativity and richness of communication. The blog authors in this study discussed the positive differences they felt when communicating with neurodivergent peers. Furthermore, the problem of double empathy, that is, the potential for misunderstandings to occur when two differing expectations of communication come together, helps to explain why efforts in interpersonal interactions should be shared.[67] In this study, being negatively different was accompanied by making high personal effort, learning to work out a personal tolerance of performing social behaviours and investing in fewer, chosen relationships. These findings complement previous autobiographical accounts of social relationships, specifically of autistic adults showing desire for social relationships, but struggling to maintain meaningful relationships, notably when autistic individuals are expected to take responsibility for social communication differences.[17] For example, there are particular difficulties with finding locations in which to socialise, that don't confound overwhelm and fatigue. This has been discussed in previous qualitative research with autistic adults, which explored differing experiences of socialising with their autistic and neurotypical peers.[68]

These findings highlight an important issue related to being autistic and finding meaningful social connection: fewer relationships and sometimes chosen aloneness are not interchangeable with loneliness. A conceptualisation of quality of life that has been developed through consultation with the autistic community supports the importance of friendships being evaluated based on satisfaction, and a person being able to be themselves with others, rather than an emphasis on the number of friendships a person has.[69] Similarly,

previous research with a large survey sample of autistic adults separated out the confusion between aloneness and loneliness.[30] In this study, loneliness was not a condition of being autistic. Rather, interpersonal wellbeing was shown to be subjective and contextual.

These findings might help to explain the high prevalence estimates of both loneliness and emotional distress for autistic adults.[12-14] These strong correlates likely reflect a particular time and set of circumstances, of identity struggle, low understanding in social networks and emotional distress. Thus, this is when ratings of lower mood, other mental ill health descriptors, reduced quality of life and loneliness seem to compound each other. In our study, dissatisfaction with relationships was associated with ill mental health for one blogger, rather than being autistic. For a second blog author, loneliness was felt after moving away from home. Together with previous research findings, this suggests that loneliness is associated with individual circumstances that cause unhappiness, without there being convincing evidence that being autistic contributes towards this unhappiness. Furthermore, the results of this study and the minimal discussion of loneliness alongside rich accounts of meaningful social connection, suggest that loneliness was not a priority topic of discussion for the autistic authors represented.

Skilled compensatory strategies that develop throughout life, while taking a toll on identity and wellbeing,[70] demonstrate an evolution of self-acceptance and emergence of strengths into adulthood. Importantly, the blog authors said that they used compensatory strategies with personal choice, rather than out of unquestioned obligation. Autistic bloggers described different transient identities that they held, which navigated the discourse of the neurodiversity paradigm, whereby autistic individuals are different but not flawed.[71,72] Therefore, self-acceptance emerged over time, in balance with the learning of some neuro-normative communication skills. Prior quantitative research has shown that loneliness ratings decrease in older autistic people,[20] which may reflect learning about the self and the development of

selective skills. Meaningful connection was achieved through investing in important relationships that had bidirectional benefits, and through avoiding scenarios of social friction and conditions of social fatigue. Mantzalas et al.[62] showed that masking can increase social inclusion, however, it can also contribute to reduced mental health and burnout. In the current study, when bloggers focused on their strengths and rationed their energy, they said they improved their social connections. One means of enjoying meaningful connection with reduced expectations to appear 'normal' was with neurodivergent peers; another was with online communities. Crompton et al.[68] explored experiences of socialising with autistic and non-autistic friends and family. Autistic adults described comfort, belonging and reduced effort 'within-neurotype' communication, due to more flexibility in the expectations of how to interact. These findings are reflected in other descriptions of widely varying communication skills used by autistic people.[66] Similarly, supportive friends and family have been shown to help autistic individuals to hold a higher degree of self-worth.[73] The qualities that facilitate social connection, of understanding, shared responsibility for communication differences and recognition of difference as strengths, can hopefully expand out of these selected groups into a more welcoming social environment within society. As one example, the findings from this study demonstrated the benefits of the higher education environment specifically. Blog authors described the ways in which they learnt a range of communication skills within their higher education studies, but also learnt about themselves, their tolerance for making social efforts, and self-advocacy. This warrants further recognition of the potential value of education systems in promoting life-long wellbeing.

What this means for clinical practice

This study was a means to explore the nature and meaning of aloneness or connection for autistic adults and the interplay with wellbeing. The main findings are as follows. First, a sense of connection is subjective and contextual. Therefore, advancement in our

understanding of loneliness is reliant upon valid loneliness measures. Together, first-person accounts of connectedness give important context to the choices made about when and with whom to socialise. We would, therefore, caution against the use of standardised scales alone to understand concepts of loneliness, wellbeing and quality of life for autistic clients, when these scales have not been standardised with autistic participants.[24,25] Such scales miss the personal meaning of relationships. Elevated scores also perpetuate a disordered and distress-laden narrative of being autistic. Ongoing work is required to refine measures of loneliness to be used with autistic people. It might be helpful to separate 'distance' in relationships – such as the number of relationships, or the ways and means of being connected – from the assumption of 'dissatisfaction' with relationships. Something else for clinicians and researchers to consider in their work with autistic clients is the extent of past learning in relationships, compensatory skill learning (when skills presume a neurotypical standard) and intent for social connection. These will inform a psychological formulation of loneliness and wellbeing.

Second, it should be assumed that autistic adults likely desire social connection, under personally meaningful conditions. Within clinical practice it will be important to explore where there are expectations for autistic people to take responsibility for social communication differences, both within therapy,[74] and in narratives throughout their lives. When presenting with co-occurring ill mental health, clinicians should explore whether social connection is being temporarily worsened.

Finally, these findings have important implications for how we learn as a society, when neuro-normative expectations can burden individuals to believe that they are 'defective,' which can lead to social withdrawal. Clinicians and researchers can adopt a critical stance on inclusion, such as through their use of language.[39,75] Additionally, we recommend further study of topics including a longitudinal, narrative exploration of self-acceptance. Future

studies might consider following young adults over a timeline of transitions through education, workplaces and adult relationships to better-understand positive and negative impacts on social relationships.

What this means for pedagogy

The findings suggest the opportunity for the higher education environment to be a platform for holistic identity development and skill learning for autistic students. Educators need to consider ways to challenge medical assumptions of disability status where these exist, which is the unfortunate required terminology for receiving education and workplace supports (Equality Act, 2010). They can consider a more positive reframing of how autistic people are understood and should challenge assumptions based on outdated deficit-based ideas, even where such terminology is still used by services. Approaches to this might include using options for mentoring or representation of neurodivergent students within disability and wellbeing services.[76] Additionally, where topics of mental health and loneliness are taught, diverse students should be reflected in the curriculum.[76] Educators might facilitate opportunities for autistic students to interact with other autistic students. This would attempt to counter predominant narratives of autism being a disorder or a morbidity, with extremely high co-occurrence with mental ill-health or loneliness. These findings also give the following clear recommendations to educators of autistic students: to describe explicitly and model what is expected in different interactions, such as within email communication, and in-person meetings. Also, to have multiple methods for being contacted, and multiple ways of hearing about available support. If in doubt, educators can ask the students what would help them, though this should not place responsibility on the student to understand what is possible within the remit of support services. These actions would inform a culture of inclusion, as has been recommended by neurodivergent students and researchers.[77] We can also anticipate a developmental trajectory of learning identity – we can understand that

students are being expected to advocate for themselves, what they need to benefit their learning and their broader wellbeing. The higher education context has the potential to foster the conditions for self-acceptance, though this does not happen in isolation of other environments or wider societal contexts.

Strengths and limitations

On reflection, we recommend the use of blog data in providing naturalistic and rich insight into personal experiences, with the approach being non-intrusive to authors who write about experiences of their choosing, with the intention of educating others, with reduced interference or bias from researchers.[40] The blogs were, themselves, a means for the authors to describe and offer explanations on personally meaningful topics.[43] We recommend consideration of such creative methods to researchers.[5,35,36] However, a limitation of accessing retrospective data is that there is no way to follow-up with participants if their meaning is unclear or misunderstood, which is particularly challenging when researchers and participants might hold different norms and expectations of each other because of neurodiversity.[67] We also anticipate that this sample offers limited representation of all autistic people. Blog authors represent those with particular technical knowledge and interest in online media and motivation to share personal experiences. For the topic of social connection, this data might favour the viewpoints of those who are more socially motivated.[38] In being able to blog, the authors may also have a range of other privileges, which were unknown to the researchers. These collective findings show the need to update our understanding of social connectedness with autistic-led research.

**Author Contributions**

All authors contributed to the study conception and design. Data collection and analyses were performed by Shannon Allen, Hannah Pickup and Bethannie Woodier with oversight from Stephanie Petty. The first draft of the manuscript was written by Stephanie Petty and all authors commented on previous versions of the manuscript. All authors approved the final manuscript.

**References**

1.      Chapple M, Davis P, Billington J, Myrick JA, Ruddock C, Corcoran R. Overcoming the double empathy problem within pairs of autistic and non-autistic adults through the contemplation of serious literature. *Frontiers in Psychology*. 2021;12:708375. https://doi.org/10.3389/fpsyg.2021.708375

2.      American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th ed. Virginia, US: American Psychiatric Association; 2013.

3.      Happé F, Frith U. Annual Research Review: looking back to look forward – changes in the concept of autism and implications for future research. *Journal of Child Psychology and Psychiatry*. 2020;61(3):218-232. https://doi.org/10.1111/jcpp.13176

4.      Pellicano E, den Houting J. Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*. 2021;63(4):381-396. https://doi.org/10.1111/jcpp.13534

5.      Fletcher-Watson S, Adams J, Brook K, et al. Making the future together: shaping autism research through meaningful participation. *Autism*. 2019;23(4):943-953. https://doi.org/10.1177/1362361318786721

6.      World Health Organization. Mental health: Strengthening our response. World Health Organization. https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response. Accessed December 6, 2022.

7.      Lever AG, Geurts HM. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2016;46:1916–1930. https://doi.org/10.1007/s10803-016-2722-8

8.      Hofvander B, Delorme R, Chaste P, Nydén A, Wentz E, Ståhlberg O. Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*. 2009;9(35). https://doi.org/10.1186/1471-244X-9-35

9.      Cooper K, Smith LG, Russell A. Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*. 2017;47(7):844-854. https://doi.org/10.1002/ejsp.2297

10.      Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*. 2016;208(3):232-238. https://doi.org/10.1192/bjp.bp.114.160192

11.      Camm-Crosbie L, Bradley L, Shaw R, Baron-Cohen S, Cassidy S. "People like me don't get support": autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*. 2019;23(6):1431-1441. https://doi.org/10.1177/1362361318816053

12.      Hedley D, Uljarević M, Wilmot M, Richdale A, Dissanayake C. Understanding depression and thoughts of self-harm in autism: a potential mechanism involving loneliness. *Research in Autism Spectrum Disorders*. 2018;(46);1-7. https://doi.org/10.1016/j.rasd.2017.11.003

13.      Hedley D, Uljarević M, Foley K-R, Richdale A, Trollor J. Risk and protective factors underlying depression and suicidal ideation in autism spectrum disorder. *Depression and Anxiety*. 2018;35(7):648-657. https://doi.org/10.1002/da.22759

14.      Mazurek MO. Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism*. 2013;18(3):223-232. https://doi.org/10.1177/1362361312474121

15.      Hays R, DiMatteo MR. A short-form measure of loneliness. *Journal of Personality Assessment*. 1987;51(1):69-81. https://doi.org/10.1207/s15327752jpa5101_6

16.   Russell D, Cutrona CE, Rose J, Yurko K. Social and emotional loneliness: An examination of Weiss's typology of loneliness. *Journal of Personality and Social Psychology*. 1984;46(6):1313-1321. https://doi.org/10.1037/0022-3514.46.6.1313

17. Causton-Theoharis J, Ashby C, Cosier M. Islands of loneliness: exploring social interaction through the autobiographies of individuals with autism. *Intellectual and Developmental Disabilities*. 2009;47(2):84-96. https://doi.org/10.1352/1934-9556-47.2.84

18. Kanner L. Autistic disturbances of affective contact. *Nervous Child*. 1943 1943;2(3):217-250.

19. Umagami K, Remington A, Lloyd-Evans B, Davies J, Crane L. Loneliness in autistic adults: a systematic review. *Autism*. 2022;26(8): 2117-2135. https://doi.org/10.1177/13623613221077721

20. van Heijst BF, Geurts HM. Quality of life in autism across the lifespan: a meta-analysis. *Autism*. 2015;19(2):158-167. https://doi.org/10.1177/1362361313517053

21. Russell DW. UCLA Loneliness Scale (Version 3): Reliability, validity, and factor structure. *Journal of Personality Assessment*. 1996;66(1):20-40. https://doi.org/10.1207/s15327752jpa6601_2

22. Bearss K, Taylor CA, Aman MG, et al. Using qualitative methods to guide scale development for anxiety in youth with autism spectrum disorder. *Autism*. 2016;20(6); 663-672. https://doi.org/10.1177/1362361315601012

23. Rodgers J, Wigham S, McConachie H, Freeston M, Honey E, Parr JR. Development of the anxiety scale for children with autism spectrum disorder (ASC-ASD). *Autism Research*. 2016;9(11):1205-1215. https://doi.org/10.1002/aur.1603

24. Petty S, Trickett A, Thompson K, Garbutt R, Saunders M. Revising our understanding of emotional distress for autistic adults; call for research. *Current Psychology*. 2022. https://doi.org/10.1007/s12144-022-03254-0

25. Ayres M, Parr JR, Rodgers J, Mason D, Avery L, Flynn D. A systematic review of quality of life of adults on the autism spectrum. *Autism*. 2018;22(7):774-783. https://doi.org/10.1177/1362361317714988

26.    Huang Y, Arnold SRC, Foley K-R, Trollor JN. Diagnosis of autism in adulthood: a scoping review. *Autism*. 2020;24(6):1311–1327. https://doi.org/10.1177/1362361320903128

27.    Harmens M, Sedgewick F, Hobson H. The quest for acceptance: a blog-based study of autistic women's experiences and well-being during autism identification and diagnosis. *Autism in Adulthood*. 2022;4(1):42-51. https://doi.org/10.1089/aut.2021.0016

28.    Mandy W. Social camouflaging in autism: is it time to lose the mask? *Autism*. 2019;23(8):1879-1881. https://doi.org/10.1177/1362361319878559

29.    Takara K, Kondo T, Kuba T. How and why is autism spectrum disorder misdiagnosed in adult patients? From diagnostic problem to management for adjustment. *Mental Health in Family Medicine*. 2015;11(2):73-88. https://doi.org/10.25149/1756-8358.1102011

30.    Ee D, Hwang YI, Reppermund S, et al. Loneliness in adults on the autism spectrum. *Autism in Adulthood*. 2019;1(3):182-193. https://doi.org/10.1089/aut.2018.0038

31.    Hong J, Bishop-Fitzpatrick L, Smith LE, Greenberg JSM, M. R. Factors associated with subjective quality of life of adults with autism spectrum disorder: self-report versus maternal reports. *Journal Of Autism and Developmental Disorders*. 2016;46(4):1368-1378. https://doi.org/10.1007/s10803-015-2678-0

32.    Botha M. Critical realism, community psychology, and the curious case of autism: A philosophy and practice of science with social justice in mind. *Journal of Community Psychology*. 2021. https://doi.org/10.1002/jcop.22764

33.    Milton DE. Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*. 2014;18(7):794-802. doi:10.1177/1362361314525281

34.    Singer J. "Why can't you be normal for once in your life?" From a 'problem with no name' to the emergence of a new category of difference. In: Corker M, French S, eds. *Disability Discourse*. McGraw-Hill Education; 1999:59–67.

35.    Brooks R, Lainio A, Lažetić P. Using creative methods to research across difference. An introduction to the special issue. *International Journal of Social Research Methodology*. 2020;23(1):1-6. https://doi.org/10.1080/13645579.2019.1672281

36.    Nicolaidis C, Raymaker D, Kapp SK, et al. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*. 2019;23(8):2007-2019. https://doi.org/10.1177/1362361319830523

37.    Baker DL. *The Politics of Neurodiversity: Why Public Policy Matters*. Colorado, US: Lynne Rienner Publishers; 2011.

38.    Nguyen T, Duong T, Venkatesh S, Phung D. Autism blogs: expressed emotion, language styles and concerns in personal and community settings. *IEEE Transactions on Affective Computing*. 2015;6(3):312-323. https://doi.org/10.1109/taffc.2015.2400912

39.    Petty S, Hamilton L, Heasman B, Fiberesima N. Social justice informed therapy and neurodiversity. In: Charura D, Winter L, eds. *The SAGE Handbook of Social Justice in the Psychological Therapies*. California, US: SAGE Publishing; in press.

40.    Jones M, Alony I. Blogs – the new source of data analysis. *Issues in Informing Science and Information Technology*. 2008;5(1):433-446. https://doi.org/10.28945/1019

41.    Miller EA, Pole A. Diagnosis blog: checking up on health blogs in the blogosphere. American Journal of Public Health. *American Journal of Public Health*. 2010;100(8):1514–1519. https://doi.org/10.2105/ajph.2009.175125

42.    Norris JE, Maras K. Supporting autistic adults' episodic memory recall in interviews: the role of executive functions, theory of mind, and language abilities. *Autism*. 2021;26(2):513-524. https://doi.org/10.1177/13623613211030772

43.    Rains SA, Keating DM. The social dimension of blogging about Health: Health Blogging, social support, and well-being. *Communication Monographs*. 2011;78(4):511-534. https://doi.org/10.1080/03637751.2011.618142

44.    Willis R. Observations online: finding the ethical boundaries of Facebook research. *Research Ethics*. 2019;15(1):1-17. https://doi.org/10.1177/1747016117740176

45.    Metzger MJ. Making sense of credibility on the Web: models for evaluating online information and recommendations for future research. *Journal of the American society for Information Science and Technology*. 2007;58(13):2078-2091. https://doi.org/10.1002/asi.20672

46.    Hookway N. 'Entering the blogosphere': some strategies for using blogs in social research. *Qualitative Research*. 2008;8(1):91-113. https://doi.org/10.1177/1468794107085298

47.    Baker P. *Sociolinguistics and Corpus Linguistics*. Edinburgh, UK: Edinburgh University Press; 2010.

48.    Bramer WM, De Jonge GB, Rethlefsen ML, Mast F, Kleijnen J. A systematic approach to searching: an efficient and complete method to develop literature searches. *Journal of the Medical Library Association*. 2018;106(4):531-541. https://doi.org/10.5195/jmla.2018.283

49.    Bauminger N, Kasari C. Loneliness and friendship in high-functioning children with autism. *Child Development*. 2000;71(2):447–456. https://doi.org/10.1111/1467-8624.00156

50.    Deckers A, Muris P, Roelofs J. Being on your own or feeling lonely? Loneliness and other social variables in youths with autism spectrum disorders. *Child Psychiatry & Human Development*. 2017;48(5):829-839. https://doi.org/10.1007/s10578-016-0707-7

51.    Malcolm M, Frost H, Cowie J. Loneliness and social isolation causal association with health-related lifestyle risk in older adults: a systematic review and meta-analysis protocol. *Systematic Reviews*. 2019;8(1):48. https://doi.org/10.1186/s13643-019-0968-x

52.     Biber D. Methodological issues regarding corpus-based analyses of linguistic variation. *Literary and Linguistic Computing*. 1990;5(4):257–269. https://doi.org/10.1093/llc/5.4.257

53.     Lexical Analysis Software. WordSmith Tools Version 8.0. Windows software for finding word patterns. http://www.lexically.net/wordsmith/downloads/ Accessed June 5, 2021.

54.     Burnard L. What is the BNC? http://www.natcorp.ox.ac.uk/corpus/index.xml Accessed August 8, 2022

55.     Biber D, Reppen R. *The Cambridge Handbook of English Corpus Linguistics*. Cambridge, UK: Cambridge University Press; 2015.

56.     Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77-101. https://doi.org/10.1191/1478088706qp063oa

57.     Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*. 2019;11(4):589-597. https://doi.org/10.1080/2159676x.2019.1628806

58.     Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: Entreq. *BMC Medical Research Methodology*. 2012;12(1):1-8. https://doi.org/10.1186/1471-2288-12-181

59.     Bruckman A. Studying the amateur artist: a perspective on disguising data collected in human subjects research on the Internet. *Ethics and Information Technology*. 2002;4(3):217-231. https://doi.org/10.1023/A:1021316409277

60.     British Psychological Society. Ethics guidelines for internet-mediated research. Leicester: British Psychological Society; 2021.

61.     Pojanapunya P, Watson Todd R. Log-likelihood and odds ratio: keyness statistics for different purposes of keyword analysis. *Corpus Linguistics and Linguistic Theory*. 2018;14(1):133-167. https://doi.org/10.1515/cllt-2015-0030

62.     Mantzalas J, Richdale AL, Adikari A, Lowe J, Dissanayake C. What is autistic burnout? A thematic analysis of posts on two online platforms. *Autism in Adulthood*. 2022;4(1):52-65. https://doi.org/10.1089/aut.2021.0021

63.     Cooper R, Cooper K, Russell AJ, Smith LG. "I'm proud to be a little bit different": the effects of autistic individuals' perceptions of autism and autism social identity on their collective self-esteem. *Journal of Autism and Developmental Disorders*. 2021;51(2):704-714. https://doi.org/10.1007/s10803-020-04575-4

64.     Hendricks DR, Wehman P. Transition from school to adulthood for youth with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*. 2009;24(2):77-88. https://doi.org/10.1177/1088357608329827

65.     Bauminger N, Shulman C, Agam G. Peer interaction and loneliness in high-functioning children with autism. *Journal of Autism and Developmental Disorders*. 2003;33(5):489-507. https://doi.org/10.1023/a:1025827427901

66.     Heasman B, Gillespie A. Neurodivergent intersubjectivity: distinctive features of how autistic people create shared understanding. *Autism*. 2019;23:910-921. https://doi.org/10.1177/1362361318785

67.     Milton DE. On the ontological status of autism: the 'double empathy problem'. *Disability & Society*. 2012;27(6):883-887. https://doi.org/10.1080/09687599.2012.710008

68.     Crompton CJ, Hallett S, Ropar D, Flynn E, Fletcher-Watson S. 'I never realised everybody felt as happy as I do when I am around autistic people': a thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*. 2020;24(6):1438-1448. https://doi.org/10.1177/1362361320908976

69.     McConachie H, Mason D, Parr JR, Garland D, Wilson C, Rodgers J. Enhancing the validity of a quality of life measure for autistic people. *Journal of Autism and Devlopmental Disorders*. 2018;48(5):1596-1611. https://doi.org/10.1007/s10803-017-3402-z

70.     Cook J, Hull L, Crane L, Mandy W. Camouflaging in autism: a systematic review. *Clinical Psychology Review*. 2021;89(102080). https://doi.org/10.1016/j.cpr.2021.102080

71.     Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, Schwartzman B. Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology*. 2017 2017;8(1):438. https://doi.org/10.3389/fpsyg.2017.00438

72.     Fletcher-Watson S, Happé F. *Autism: a new introduction to psychological theory and current debate*. London, UK: Routledge; 2019.

73.     Hurlbutt K, Chalmers L. Adults with autism speak out. *Focus on Autism and Other Developmental Disabilities*. 2002;17(2):103-111. https://doi.org/10.1177/10883576020170020501

74.     Petty S, Bergenheim M-L, Mahoney G, Chamberlain L. Adapting services for autism: recommendations from a specialist multidisciplinary perspective using freelisting. *Current Psychology*. 2021. https://doi.org/10.1007/s12144-021-02061-3

75.     Bottema-Beutel K, Kapp SK, Lester JN, Sasson N, J., Hand BN. Avoiding ableist language: suggestions for autism researchers. *Autism in Adulthood*. 2021;3:18-29. https://10/gjk3r6

76.     Marshall S. *A Handbook for Teaching and Learning in Higher Education: Enhancing Academic Practice*. London, UK: Routledge; 2020.

77.     Dwyer P, Mineo E, Mifsud K, Lindholm C, Gurba A, C. WT. Building neurodiversity-inclusive postsecondary campuses: recommendations for leaders in higher education. *Autism in Adulthood*. 2022. https://10.1089/aut.2021.0042

**Tables**

**Table 1** *Search terms used to create a specialised corpus of personal descriptions of social connection written by autistic blog authors*

| Social connection synonym | Searched term |
| --- | --- |
| abandoned | abandon |
| alienated / alienate / alienation | alienat |
| alone / lone / lonely / loneliness | lone |
| apart / parted | part |
| belonging / belong | belong |
| close / closeness / not close | close |
| communication / communicate | communicat |
| companion/ company / unaccompanied | compan |
| connected / connect / disconnected | connect |
| cut-off | cut-off |
| disembodied | disembodied |
| dismissed | dismiss |
| excluded / not included / exclude / secluded / seclude | clude |
| fit in | fit in |
| friendship / friends | friend |
| interaction / interact | interact |
| isolated / isolating / isolation | isolat |
| left | left |
| myself | self |
| on my own | own |
| rejected / reject | reject |
| relationship | relationship |
| secluded / seclusion | seclu |
| segregated / segregate / segregation | segregat |
| separate / separated | separate |
| social support | social |
| solitary | solitar |
| solitude | soltud |
| support /social support / supported / | support |
| uncared for / care | care |
| unloved | unlove |
| unwanted | unwant |

withdrawn / withdraw / withdrawal                        withdraw

**Table 2** *Top 15 keywords in the descriptions of social connection in personal descriptions written by autistic bloggers, ordered by 'keyness'.*

|    | Keyword | Strong neighbouring words | Freq. | Log likelihood (**keyness**) | Log ratio |
|----|---------|---------------------------|-------|------------------------------|-----------|
| 1  | Autistic | Students | 81 | 1,161.47 | 12.40 |
| 2  | Learned | Skills | 52 | 298.54 | 5.56 |
| 3  | Relationships | | 31 | 139.63 | 4.64 |
| 4  | Allistic | | 7 | 118.52 | 1,062.45 |
| 5  | Functioning | | 16 | 109.16 | 6.36 |
| 6  | Social | | 52 | 98.42 | 2.56 |
| 7  | Nonverbal | | 7 | 97.80 | 12.02 |
| 8  | Friends | | 33 | 96.84 | 3.43 |
| 9  | Communication | Skills | 23 | 89.34 | 4.17 |
| 10 | Behaviours | | 12 | 88.05 | 6.74 |
| 11 | Neurotypical | | 5 | 84.66 | 1,061.97 |
| 12 | Boundaries | Respect | 16 | 79.79 | 5.00 |
| 13 | Trauma | | 11 | 79.16 | 6.63 |
| 14 | Disabled | | 17 | 76.17 | 4.62 |
| 15 | Feel | | 36 | 25,375 | 76.01 |

**Table 3** *Concordance lines showing example descriptions of social connection by autistic bloggers, shown in order of keyword strength.*

| Keyword | Example concordance lines |
|---------|---------------------------|
| Relationships | I have made the successful **relationships** in my life work... making the important **relationships** work in my life... having deep supportive **relationships**, as well as the willingness to engage... bidirectional benefits of deep **relationships** with the right people... much of that has meant rejecting generic **relationships**, or connections with people who do not mean anything to me... supportive, beneficial even reparative **relationships**. |
| Social | I do not need the added stress of feeling like I have to go to all the out of work **social** engagements… the issue is that autism can place such a crippling block on your **social** |

energy… late diagnosed autistic women like me float around the fringes of **social** circles… you were never around, you never texted anybody back, you caused unnecessary **social** friction.

| | |
|---|---|
| Friends | I can't say that I don't have **friends**. I used to think that it was a necessary part of my autism not to have **friends**… one of my closest **friends**… while I am bad at making **friends** and don't have very many, I am not lonely… more than half of my best **friends** were on the spectrum… two of my best **friends** have AD(H)D. |
| Communication | my people skills and my **communication** skills were much more limited… I told you that I can not see those subtle forms of **communication**... clue-based **communication** that allistic people like so much is often very confusing… I need **communication** to be very blunt... NT expectations and assumptions about verbal and nonverbal **communication** and social interaction norms played a huge role in the barriers I experienced. |

**Table 4** *Themes and subthemes in personal descriptions of social connection by autistic bloggers with example quotes.*

| Themes | Example quotes |
|---|---|
| **1 Barriers to meaningful social connection** | |
| 1.1 Different communication | "I really need things stated to me very clearly and directly, and that is definitely a struggle for allistic people. I can't count how many times I have inadvertently overstepped a boundary simply because I didn't know it was there." (Blog 5) |
| | "Dealing with social issues so often feels like fighting a war with my brain. It's autistic tendency versus the fear of losing friendships that I value." (Blog 3) |
| 1.2 Unclear autistic identity | "Being autistic, saying I am autistic, means everything about me doesn't matter to a non-autistic person, especially when it comes to things that are about being autistic." (Blog 13) |
| | "I've spent my life never quite fitting in with the world around me. Late diagnosed autistic women like me float around the fringes of social circles… I am too weird to be normal but not autistic enough to be autistic?" (Blog 18) |
| 1.3 Learned withdrawal and aloneness | "Don't attempt to be part of a sociable group. It never goes well. At some point something bad will happen because of misunderstandings or personality conflicts and you will be left feeling like you're to blame." (Blog 1) |

| Themes | Example quotes |
|---|---|
| | "But, you know, after you fail and fail and fail again, eventually you lose the motivation to try any more when you know the outcome won't be any different!" (Blog 4) |
| **2 Improving connection** | |
| 2.1 Self-acceptance | "It took discovering alternative, even 'odd', or 'strange' ways of interacting with the world, that worked for me, for me to realize what and how I did want to interact. It took throwing out the NT 'rulebook' and creating (and co-creating) a new one that worked with both my limitations and my abilities, whatever they were... I'll take my mental health, my peace of mind, and strong sense of self over 'fitting in', or 'being successful' in the traditional, financially independent, career-oriented sense, any day." (Blog 4) |
| | "…my inability to fit in that normalcy really looked wonderful. I genuinely thought that the key to happiness was achieving some standard of normal. Of course, happiness has come from self-acceptance and self-love." (Blog 5) |
| 2.2 Opportunities within education | "I'm starting to see that while my university career might not have yielded the typical benefits, or purpose, it has resulted in my gaining so many people skills and communication skills that are useful any time I run into conflict in my personal life, big or small." (Blog 4) |
| 2.3 Chosen relationships | "I care about maintaining my friendships so much, because I've worked really hard to get to this social point in my life, and I'm doing so much better with it than I once was." (Blog 3) |
| | "I see posts from folks all the time who get zero support from their families or friends, people who disrespect their struggles or request for accommodation, and it's really sad. I am grateful that I've been able to curate this group of people in my life." (Blog 6) |