

# The Lost Generation of Autistic Women's Experiences of Secondary School: An Interpretative Phenomenological Analysis Approach

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This paper focuses on the “lost generation” of autistic women's experiences of secondary school using an interpretative phenomenological analysis (IPA) approach. Autistic women were supported through inclusive research practices to share their experiences of secondary school as an unrecognised autistic child, as captured through an online questionnaire and semi-structured interview. The core features of the cohort included a diagnosis of autism post eighteen years old, and attendance at a mainstream secondary school in the United Kingdom. The findings highlight the participants' difficult experiences, including bullying, difficult relationships with peers, sensory difficulties within their school environment and processing differences within their learning. The findings also showed two areas that positively contributed to their school experiences, including friendships and positive relationships with teachers. Discussions centre on the benefits that autistic adults bring to informing educational enquiry and why the phenomenon of the lost generation of autistic girls is still a current concern.

*Keywords:* autism, autistic girls, secondary education, special educational needs, interpretive phenomenological analysis

The topic of this article was inspired by the poem *We Are the Lost Girls* written by C. J. Artist (please see Appendix) and focuses on the “lost generation” (Lai & Baron-Cohen, 2015) of autistic women's experiences of secondary school — women who were not identified as autistic until adulthood and, as such, spent their schooling unrecognised and unsupported in relation to their later autism diagnosis. This enquiry is guided by two research questions:

1. What were the secondary school experiences of unidentified autistic women?
2. What contributed to the women's positive and difficult experiences of secondary school as an unidentified autistic child?

Autism is a social communication and processing difference that informs how someone communicates, relates to other people, and processes their sensory environment (American Psychiatric Association, 2013). The current autism prevalence is estimated as three males to every one female, with women disproportionately denied a clinical diagnosis when compared to their male peers (Loomes et al., 2017). This diagnostic difference is now recognised as being attributed to a gender bias in how autism is conceptualised (Milner et al., 2019). Hence, the phenomenon of missed diagnosis is particularly relevant to autistic girls and women. This background suggests some of the reasons why this phenomenon exists and its importance in relation to educational opportunity.

The early understanding of autism was derived from Kanner's (1943) and Asperger's (1944/1991) observations within small- scale studies, both of which focused on the language, communication and repetitive behavioural patterns of boys. Consequently, autism was originally thought to be a predominantly male diagnosis (Milner et al., 2019). Thus, research was often carried out with a majority male participant sample (Harrop et al., 2018), with many diagnostic tools developed in line with masculine behavioural characteristics (Navarro-Pardo et al., 2021). In response to this perceived high male prevalence, research objectives focused on biological sex differences and explored autistic male brain theories (Baron-Cohen & Hammer, 1997; Baron-Cohen, 2002). Over time, the understanding of autism has changed. It is now recognised that there are no biological brain differences between autistic males and females (Grove et al., 2017) but, rather, very subtle differences within social motivation and the navigation of social situations (Gould, 2017; Mademtzi et al., 2018).

When considering why autistic women are “missed” to diagnosis, it is helpful to note that overt autistic behavioural markers form part of the diagnostic criteria. For instance, the presence of restrictive and repetitive bodily movements (American Psychiatric Association, 2013). In western culture, there is a tendency to assign certain behavioural traits based on male and female gendered stereotypes (Robinson, 1992). One such assumption is that girls are more pro-social than boys (Gould, 2017). To meet social demands, autistic people are thought to mimic the behaviour of their peers,

sometimes referred to as “masking” or “camouflaging” (Hull et al., 2017). This compensatory strategy is considered problematic due to being both physically (Livingston et al., 2019) and emotionally (Tierney et al., 2016) exhausting, in addition to being associated with mental health challenges (Lai et al., 2021). Hence, the act of masking makes identifying and supporting autistic girls difficult, because they may not always appear overtly autistic (Livingston et al., 2020; Whitlock et al., 2020) but instead are mistakenly perceived as shy, awkward or immature (Attwood, 2008).

It is recognised that having access to the supports and accommodations needed to learn enables choice in future employment and later contribution to society (Terzi, 2007). Conversely, not receiving a timely diagnosis nor appropriate support has implications for the educational opportunity of autistic children. There are many elements within the school day that create barriers for autistic children. These include how lessons are taught within busy classroom environments (Underhill et al., 2019), the impact of sensory processing difficulties on attention and learning (Howe & Stagg, 2016), and complications with forming friendships and sustaining relationships when compared to peers (Santillan et al., 2019).

Not being identified in line with a required autism diagnosis has wider social implications. Due to social communication differences impacting the understanding of social rules in the playground (Hoover, 2015), autistic children can become a vulnerable target to peers (Cook et al., 2018), with verbal and physical bullying commonplace (Hebron et al., 2017). Additionally, not receiving appropriate school supports can lead to autistic children developing a decline in school engagement, an increase in distressed behaviour and, for some, school exclusion (Brede et al., 2017). Without access to a timely diagnosis, unrecognised autistic girls are not offered the opportunity for support, accommodation or sympathetic understanding of their needs and are instead left to navigate their schooling and face these repercussions on their own.

This article explores the lost generation of autistic girls’ experiences of secondary school utilising an interpretative phenomenological analysis (IPA) approach. An online questionnaire and semi-structured interview capture the secondary school experiences of the participants, organised under superordinate and subordinate themes with corresponding quotes. Thereby, preserving the individual voice of each participant in addition to the collective experiences of the women overall.

### **Materials and Methods**

This study adopts an IPA approach outlined by Howard et al. (2019). Ethical approval was granted by the University of Roehampton, and informed consent was obtained from all participants prior to collecting data. A mixed-method design consisting of a qualitative online questionnaire and

a semi-structured interview was adopted. An inclusive research approach was utilised (Aldridge, 2014, 2016; Ellard-Gray et al., 2015). This included clear, jargon-free language in the online questionnaire and a choice of either a text chat or online face-to-face interview, through a platform of the participant’s choosing for the semi-structured interview. These design features were incorporated to create an accessible research environment that accommodated the participants’ self-governance of sensory requirements, supported the participants’ preferred communication style and provided a comfortable and familiar setting in which to share their personal lived experiences.

### **Interpretative Phenomenological Analysis (IPA)**

IPA is a qualitative research approach that is underpinned by phenomenology, which values lived experiences to be the ultimate objective of philosophical examination and research (Husserl, 1913/1931). During the analysis process, the researcher considered the participant’s interpretation of their personal experiences of secondary school, capturing the unique individual experience of each participant, in conjunction with the shared experiences of the collective.

### **Participants**

Fourteen participants were initially recruited through online social media platforms. The inclusion criteria required all the participants to be women (female assigned at birth) and to have completed their secondary education (aged 11 to 16) in England. They also must have received an autism diagnosis or a variation, such as Asperger’s syndrome, through an NHS or private medical assessment as adults (post 18 years old). Three participants were also included in the initial questionnaire who self-identified as autistic owing to the barriers that women face in gaining a diagnosis. However, to create a homogenous sample, these participants were not taken to interview. Subsequently, eight women who had received an autism diagnosis as an adult were interviewed.

### **Initial Questionnaire**

Through an online questionnaire, participants provided brief demographic information, for example age of diagnosis, and co-occurring conditions, followed by a paragraph outlining their experiences of secondary school. The amount of detail given by participants within the questionnaire ranged from brief to detailed first-hand accounts. All questionnaire data were anonymised and organised through the online platform and data downloaded in both individual and group formats. The accounts were analysed in line with IPA recommendations (Howard et al., 2019) and themes allocated according to frequency, as shown below, with the frequency of occurrence in brackets.

### ***Superordinate Themes***

The superordinate themes included Friendship Difficulties (8), Emotional Health (7) and Self-Harm/Suicide (5).

### ***Subordinate Themes***

The subordinate themes included, Academically Able (4), Bullied (4) and Small Circle of Friends (4).

### **Semi-Structured Interview**

The above themes were then used as a guide to form provisional questions for the semi-structured interview. Eight participants were interviewed with their choice of method. Five of the participants completed an online face-to-face interview, and one participant completed a telephone interview, with the remaining participants completing an online text/email interview. During interview, some women shared that recalling memories from secondary school was difficult, partly due to the time passed, but also due to the traumatic nature of their experiences impacting memory recall. In response to these participants, an interview technique was adopted that supported systematic memory recall from the starting point of preparing for school in the morning. The participants shared their adult interpretation of their secondary school experience, which is not possible when reflecting on experiences as a child.

Each participant's data was anonymised, initially by number and later by assigning a flower "name". Flowers were chosen by the researcher to reflect growth and strength of the participants. Where appropriate, the flower names were chosen to reflect the participants' interests during their schooling. Through the coding process, it became evident that being "academically able" was a core characteristic of this cohort. Therefore, due to participant eight attending a specialist learning provision, it was decided that she had a different trajectory to the other participants, so her results were removed from the data. The remaining seven participants' data were analysed through a consistent method, as shown below with the frequency of occurrence in brackets.

### ***Superordinate Themes***

The superordinate themes included Emotional Health Considerations (7), Bullying and Difficult Peer Relationships (6), Environmental Considerations (6), and Lesson/Learning Considerations (6).

### ***Subordinate Themes***

The subordinate themes included, Friendships (5), and Positive Relationships with Teachers (5).

## **Results**

### **Superordinate Themes**

The superordinate themes form the most frequently discussed experiences of secondary school for the women as a collective across all data.

### **Emotional Health Considerations**

The first theme, "Emotional Health Considerations", reflects a grouping of the codes "Masking": hiding autistic behaviour or mimicking peer behaviour; "Emotional Health": the experience of anxiety or fear; and "Mental Health" as marked by suicidal intention and self-harm into one category.

The three-category formation was considered appropriate as they are all closely linked processes, although it was noted that they are different in both intensity and experience. The impact of emotional health difficulties was evident across all interviews. For instance, Dahlia shared: "*It was a really depressing time, like every time I think about it, I don't have any real memories, but I have a real sadness.*" Whilst Simbelmyne expressed, "*There was a disproportionate amount of stress over everything really, all the way through school, it's only in retrospect I look back and think those are like pathological levels, like you would be diagnosed with an anxiety disorder nowadays.*"

The experience of emotional health ranged from anxiety about being left on their own. For instance, Jasmine shared, "*It was the feeling of being left on my own with no one to chat with, even on a shallow level — fear, not feeling.*" Whilst Ren explained that she felt pressure to mask her anxiety:

*I would just zip up all my feelings, squash it all down. I was a ball of anxiety constantly, you know, very heightened, very stressed about everything, and I think the way that I responded to that was to just, to sort of, suppress, people please.*

There was a clear distinction between the emotional impact of fear and anxiety and the development of more challenging mental health difficulties as demonstrated by Simbelmyne, who responded to difficult emotions through self-harm — "*I used to bleed a lot and it was a very spontaneous on the spot coping mechanism, a maladaptive coping mechanism when I was overwhelmed and stressed.*" Furthermore, Simbelmyne compared her experience of mental health difficulties to the film *The Girl Interrupted*, in which the lead character is shamed and disbelieved:

*[A] Young woman who is self-harming she's attention-seeking, she must be hysterical, she is making it up so that people will look at her, she is probably some kind of whore who doesn't*

*know how to behave. It was just this incredible negative stereotyping.*

Overall, it was apparent that emotional health considerations were a prominent factor in the women's secondary school experiences, with the following themes likely contributing to these difficulties.

### ***Bullying and Difficult Peer Relationships***

The category "Bullying and Difficult Peer Relationships", combines the codes "Bullying": verbal and physical bullying; and "Difficult Peer Relationships": difficulties relating to and understanding their peers' intentions, difficulties forming relationships with peers.

The types of difficulties experienced by the participants ranged from not feeling like they were able to connect with their peers, with Rose stating: *"I wanted a friend, but just didn't know how to get one."* through to taunting, with Capellan explaining, *"It was generally just all sort of, yeah, making snide remarks about you."* and physical bullying. Dahlia recalled, *"I had had my hair set on fire; I was spat at; I was basically excluded; I didn't have any friends, and I was mocked. I don't think I actually realised I was being mocked."*

It was evident that some of the women found maintaining peer relationships difficult. Simbelmyne explained that a friend of hers, *"wanted to hang with the popular party crowd who were always going out and getting drunk on Friday nights, as I sat in the library and talked about hobbits and was quite depressed"*. As well as Ren finding certain children in her class unpredictable, *"I found her incredibly difficult, because she pushed boundaries . . . she would do things, like she would like poke or like hit, she was only messing around, I know she was, but in that slightly on the edge way."*

Commonly, the participants shared more subtle forms of bullying. Capellan explained: *"They were always talking behind your back and saying things about you or commenting on your appearance, and it felt like nothing you ever did was kind of, yeah would make them kind of think differently about you."* Whilst Dandelion shared that she misinterpreted the phrases the children used to mock her: *"There was a little while when I thought 'ankle biters' was a compliment; it turns out it is not a compliment."* It should be noted that all accounts of bullying from subtle taunting through to physical acts negatively impacted the women's emotional health.

Some of the women expressed that they retaliated against their bullies. Ren recalled a memory of a group of children following her home after school, challenging her to fight. She described always feeling like she was *"in the wrong"* and that she must have done something to cause the fight. She said she *"didn't even think of calling the police"*, explaining: *"I'm not violent at all, but you know, when I'm like, right-in-it, I'll fight the battle"*. Capellan also shared that a peer at

school *"cycled up and started harassing us, so I kicked him, and after that the harassment stopped"*.

### ***Environmental Considerations***

The participants' experiences of their school environment predominantly related to how they managed the sensory demands of a mainstream school. Many of the women emphasised the negative impact that noise had on their learning. These results are in line with the findings of Howe and Stagg (2016), who stated that the autistic in their study would have a physical reaction to noise and become distracted. In turn, there was a shared commonality among the participants to seek quiet spaces away from other people. These considerations highlight the importance of understanding the impact of noise within the physical school environment for the inclusion and wellbeing of all students.

Ren explained that she *"found school quite chaotic and quite unpredictable"*. Jasmine shared that the classroom was, *"noisy, disruptive, and often very tedious. We had to sit in rows, which meant you were often wondering what happened behind you"*. This indicated that not only was the physical environment difficult for her but also her positioning in relation to her peers also impacted her negatively. The sensory environment was also of importance with Rose sharing:

*I didn't like the short-pile carpets in the new buildings, as the feel of the chairs rubbing across them was not nice. I really didn't like the smell of the swimming pool or the art department, even though the lessons themselves could be OK.*

There was a common shared experience of gravitating towards the library for some quiet time away from other people. Rose explained:

*I used to sit in a cupboard in one of the corridors. I remember doing that for a long time. I just sat there and thought for as long as I could. After about three years I found the school library, and suddenly a whole world was opened up to me.*

Simbelmyne shared an appreciation of outside spaces, *"I liked when I was allowed sort of quiet time . . . I liked quite a lot of the green spaces, and the quieter spaces."*

When considering the women's collective experience, it became evident that their environmental difficulties were largely associated with their sensory challenges, with quiet spaces away from other people sought that reduced these demands.

### **Lesson/Learning Considerations**

The theme of Lesson/Learning Considerations outlines the barriers to learning shared by the women. Dahlia explained that “*as soon as they [her teacher] give an instruction, I completely zone out or I don’t understand*”. There was also an indication that, if a subject was delivered in a way that was not enjoyable, they did not enjoy the lessons, despite liking the subject itself. Capellan explained:

*[I did not like] science not so much because quite often you were forced into groups to do that, and I always found that quite difficult, especially if I didn’t have a member of my friends’ group to go to. I found it really hard working with someone I hadn’t spoken to before.*

For some of the women, there was a difficulty coming up with new ideas in their work. For instance, Rose shared, “*The problem at GCSE was using my imagination to try and come up with new things without a starting point. That was really hard.*” Capellan indicated that she, “*used to do a lot of my own kind of experiments and studies and things. And, in some ways, I learnt more outside of school than I did in school, and I certainly enjoyed it more.*” Dahlia explained how she would catch up on the missed work in the lessons at home, “*You know, get the text-book out and learning it cover to cover and spending like, waking up super early and going to bed super late to make sure I’ve learnt the whole textbook.*” Jasmine shared that she had a meltdown during her religious education lesson and instead was allowed to self-teach the subject in the library, which she “*really liked*”. She preferred “*doing [her] own thing*” to attending classes.

It was evident from the women’s recollections that despite being academically able during their schooling they experienced differences in the way that they processed their lessons, indicating a need for clear instructions and a preference for independent learning.

### **Subordinate Themes**

The subordinate themes are categorised by a lower frequency than the superordinate themes and give an insight into some positive elements of the women’s secondary school experiences.

### **Friendships**

This theme combines codes “Friendships” and “Friendship Qualities” under the singular category “Friendships”. The women shared many difficulties with their friendship groups. Rose explained, “*I have never had a group of friends. There was one girl I became friends with who went to choir, and we sometimes sat on the field together.*” Dahlia shared difficulties connecting with friends: “*There was this girl . . . she was my friend in year 10 and 11, but she was very quiet,*

*she was alright but there was no real connection there.*” Simbelmyne explained that despite the initial difficulty forming friendships, it did become easier as she grew older:

*Moving into the top end of the age group, it was easier to keep a small group of friends. I had managed to get a little bit better at making friends, and I was friends with a group of girls in the year below me.*

Despite these difficulties, many of the women also had a close friend or a small group of friends that were supportive or shared a common interest. Capellan explained:

*I was always the very quiet one in the class, although I did have some friends. We had a kinda small group of friends that used to just kinda stick together. We were all pretty much in the same boat, just being a bit quiet, on our own.*

One element that shone through Ren’s interview was that the friends she had, stood out from the majority, recalling that they were “*kind people*”. When explaining this further she said:

*They were straightforward, I think, relatively straightforward. They weren’t complex social creatures. They weren’t manipulative. They weren’t, you know, hot/cold. They were fairly, I mean nobody’s completely, but they were fairly consistent.*

### **Positive Relationships with Teachers**

The last theme considers what contributed to having positive relationships with teachers. The reasons given as to why certain teachers stood out over others largely centred on common interests or the teaching style of the teacher. Simbelmyne shared, “*I think that the teachers I liked best were just the ones who gave me good grades for the subjects I liked the most.*” Dahlia explained that she liked her English teacher because she was “*a big feminist, and we connected on that*”. The way the teachers showed kindness was also appreciated, with Rose explaining:

*One of the games teachers was the kindest she’s ever been to me. I chose the sports I did based on how much I liked (or didn’t hate) them. I think she appreciated the fact that I didn’t just follow the crowd.*

Ren shared the appreciation for a teacher who delivered clear lessons, with her feelings towards the teacher largely associated with the lessons she liked. “*The thing I liked was they were clear, and I think subject, either a subject*

*like science . . . I'd be more inclined to be interested, therefore feel positive towards the teacher."* Capellan appreciated her geography teacher due to him standing out as socially different to the others. *"He was just kinda, really kind of slightly (laugh) kind of stereotypical, slightly, what's the word, absent-minded professor type, and I just found that, we all just found that, quite endearing"* (laughing).

These recollections highlight the complex difficulties faced by academically able girls who are not recognised in line with a timely autism diagnosis.

### Discussion

The findings drawn from this research highlight that the participants experienced many difficulties throughout their schooling, including bullying, difficult relationships with peers, sensory difficulties within their school environment and processing differences within their learning.

### Emotional Health Considerations

Emotional health difficulties were experienced by all the participants, with the impact and severity varying from high anxiety and fear through to suicidal intention and self-harm. In line with research on the mental health characteristics of autistic children (Skokauskas & Gallagher, 2012), many of the participants in this study experienced intense emotions throughout their secondary school education. The participants also demonstrated internalisations of their emotions, for instance Jasmine would worry that she was going to be left on her own in the playground, whilst Ren consciously repressed her emotions so nobody would be able to see how she was feeling, thereby masking her difficulties. The varied nature of the participants' emotional processing highlights the complex nature of their autistic experiences.

Emotional health is often discriminated against and regarded as a deficit of the individual, in a similar way that autism is also stigmatised (Grinker, 2020). The negative connotation of impacting emotional health was illustrated by Simbelmyne when sharing identification with a film character whose emotional health difficulties were disbelieved by those around her. It is recognised that many women are only diagnosed autistic after experiencing impacting emotional health difficulties (Tint et al., 2017). This is problematic when considering how emotional health concerns hinder a child from achieving their full potential (Holcombe & Plunkett, 2016) and may also contribute to the subsequent barriers that autistic adults face when finding and sustaining appropriate employment (Scott et al., 2019). From these discussions, it is evident that the core considerations pertain to the necessary early identification of autistic girls and early response to emotional health concerns, so that action can be taken to support and reduce their occurrence.

### Bullying and Difficult Peer Relationships

Understanding the experience of bullying is important as it has been shown to impact children's active participation in school (Adams et al., 2016). Many of the participants reported impacting levels of bullying that ranged from name-calling through to physical deliberate acts, including physical altercation.

Consistent with findings outlined by Hoover (2015), some of the participants shared feeling confused about why they did not form relationships with their peers in the way that other children did. The participants shared varied responses to being bullied. Some of the women were passive and avoided their peers, whilst others shared that they did not recognise that the bullying was taking place until they had later reflected on the social situation. However, several of the participants recalled not shying away from bullying or confrontation. These types of behaviours directly challenge stereotyped preconceptions that autistic girls are shy and timid (Attwood, 2008) and, as such, warrant further attention within future research.

### Environmental Considerations

It was found that there were significant environmental considerations within the physical learning environment and school building that impacted the participants' experience of school. Many of the women placed an emphasis on the impact of noise. These results are in line with the findings of Howe and Stagg (2016), who stated that the autistic children in their study would have a physical reaction to noise and become distracted. In turn, there was a shared commonality among the participants to seek quiet spaces away from other people. These considerations highlight the importance of understanding the impact of noise within the physical school environment for inclusion of all students.

### Lesson/Learning Considerations

The learning considerations that surround autism tend to focus on the need for social communication and sensory regulation supports rather than learning style. However, the women in this study showed a definite preference for how they learnt, particularly regarding working independently. This style of learning was demonstrated through exploring topics, revising or catching up on what was taught in the classroom through independent self-directed study. None of the women received help during their secondary schooling for their learning, sensory processing differences or social communication needs. It could be considered that their academic achievements hindered receiving support at school, with environmental and learning accommodations overlooked, due to their grades being on par or surpassing their peers. Thus, in developing a broader understanding

of autism in line with female autistic experience, it is important to consider how autistic children who are academically able learn. This is important, not because the student's grades need improvement, but because of the evident emotional and mental health implications that the school environment and learning styles have on the autistic individual, whether demonstrated overtly through meltdown and self-harm or covertly through high anxiety and upset.

### ***Friendships***

The participants placed varied importance on the friendships they formed during their secondary education. In line with Cook et al. (2018), some of the women wanted to make friends but did not know how to connect with their peers. Some of the participants said that their friends either did not fit the traditional popular characteristics of the time or that they shared common interests. Additionally, throughout several accounts, the notion of "being kind" strongly materialised as an important quality of their friendship groups. There was solidarity within the friendship circles of the autistic women, with a common acceptance due to experiencing similar difficulties to their own. Some participants were very loyal to their friends and saw them as a safety within shared lessons. Therefore, considering the role that positive and meaningful relationships have on an autistic child's experience is critical when supporting the positive aspects of school and fostering positive emotional health.

### ***Positive Relationships with Teachers***

Previous research has considered teacher and child relationships in relation to academic achievements and their informed understanding of children's autistic behaviours (Kasari et al., 2016). The positive relationships between teachers and autistic children to support positive school experiences, although a lesser researched area, is, nevertheless, an important factor. As with friendship preferences, the notion of "being kind" was also reflected in the relationships with their teachers, with positive feelings attributed to their teacher's kindness and support or a shared interest. As such, it became evident that positive teacher relationships supported the participant's enjoyment of school. This demonstrates the benefit of time taken to connect with autistic students through a common interest, thereby promoting more opportunity for positive secondary school experiences through fostering feelings of "kindness" and support.

### **Conclusion**

The experiences of unrecognised autistic children as shared from adult recollection are not often included in research. Thus, this article has provided a unique historical insight into the "lived" secondary school experiences of the "lost girls": women who recalled what it was like to be at school unidentified to their later autism diagnosis.

The women's experiences of secondary school included difficulties understanding verbal instructions in the classroom, coping with excess noise within the school environment and forming and sustaining relationships with their peers. It is important to emphasise that these women as children were all left to navigate social and environmental school demands independent of support. Consequently, this had a detrimental impact on the emotional wellbeing of the participants, with them reporting high anxiety, fear of social situations, being isolated, having suicidal intentions and self-harm. This highlights the importance of post-diagnostic emotional health support for late-identified autistic women due to the repercussions of limited support growing up.

When considering autistic people's participation in research, it is important to recognise individual experience in conjunction with that of the collective. This research has demonstrated that autistic adults bring a unique insight into what it is like to be an autistic child from a mature reflexive position. This perspective enables valuable learning that could inform actionable supports for autistic girls in education today. In accordance with the call for more participant-informed research (Fletcher-Watson et al., 2019), it is necessary for future research to continue to challenge the stereotyped depiction of autism by considering the lived experiences of girls and women throughout their lifespan. Through gaining a better perspective of what it means to be an autistic girl, it will help inform greater identification and more appropriate supports for this cohort. Lastly, it is also worth noting that further research is warranted into how schools accommodate autistic children. This includes a comprehensive understanding of the impact that hypersensitivity to noise has on attention and wellbeing. In addition to the development of inclusive pedagogy approaches that meet the specific learning and wellbeing requirements of academically-able autistic girls within the mainstream classroom.

The conversations surrounding the "lost autistic girls" are not easy. They are informed by a complicated history that has often excluded girls and women. It is only through challenging the stereotyped assumptions regarding autism that new progressions of thought, supports and appropriate diagnostic tools for autistic girls can be developed, thereby guiding the lost girls home, so they can be supported to positively recognise the contribution that their autistic thinking brings to the world.

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**Appendix**  
**We Are the Lost Girls**

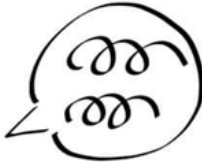
A Poem Written and Illustrated by Artist, C. J. (2022)

We are the Lost Girls

We are the Lost Girls.  
The lost generation.  
The girls they looked straight at but did not see.  
The girls they missed,  
The girls not diagnosed with Autism.



We are the girls who copied your words,  
Copied your words so well you thought we knew what to say.  
We are the girls who copied your actions,  
Copied your actions so well you thought we knew what to do.  
We never knew. We still don't.



We are the hidden chameleon girls,  
We changed our true colours to be happy.  
We changed into masks to be normal.  
We changed into actresses to belong.  
We played so many roles we became what everyone else wanted.  
We lost ourselves to fit in without even realising what we had done.



Lost Girls feeling odd, different and trying to fit in,  
Anxiety causing us to feel like running sitting still,  
Depression causing days to blacken and life to narrow,  
Helplessness and despair causing us to fight for our own existence,  
Anger that we could have been helped sooner so we wouldn't have struggled.



Lost Girls who never had a chance but made it work somehow,  
Too normal to be given help, but too different to be good at things.  
Lost Girls who had to learn on our own,  
Because no one realised we needed teaching.  
Lost Girls who learnt from trial and error, mostly error,  
Because we didn't even know what we did not know.  
Lost Girls who found so called "simple things" difficult,  
Lost Girls gliding like swans hiding frantically moving legs beneath,  
Hiding how much effort we were putting in just to grow up and keep going in life.



Lost Girls being told our children have Autism and realising we have it too,  
Lost Girls with lives we worry our daughters and sons are going to have,  
Lost Girls trying to protect you from the heartbreak we feel,  
Grieving our previous perceptions of reality,  
Trying to make the most of the rest of our lives.



But there is something worse than our lives as Lost Girls,  
It is not that there were Lost Girls suffering years or decades ago,  
It is that there are girls today who do not even know that they are lost,  
Girls without hope of diagnosis, education or jobs,  
Girls without hope of reaching their full potential,  
Girls without hope,  
Girls today who are Lost Girls.



These girls must be found,  
These girls must be diagnosed,  
These girls must be nurtured.  
Then the lost generation can end with me.  
Then I can be the last of the Lost Girls.  
Then my suffering will not be their suffering.  
Then they can have the help I never got.  
Then all girls can come home.

