

'Living in a world that's not about us': The impact of everyday life on the health and wellbeing of autistic women and gender diverse people

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Abstract

Background: Autistic women and gender diverse people have specific needs related to their physical and mental health. They also experience more barriers to accessing services. While there are autobiographical accounts of the 'invisible' challenges that autistic women and gender diverse people face day-to-day, there has been limited research that explores how these experiences impact health and wellbeing.

Objectives: This study aimed to understand the everyday experiences of autistic women and gender diverse people, and their impact on health and wellbeing.

Design: Qualitative methods were used to elicit rich information about the unique experiences of autistic women and gender diverse people.

Methods: We conducted semi-structured interviews with 31 autistic adults. The data were analysed using reflexive thematic analysis.

Results: We identified 3 themes and 10 subthemes. Our first theme described 'all the stuff that you have to do to get through life', including managing domestic tasks, parenting, unique health needs and co-occurring physical conditions. The second theme outlined the impact of 'living in a world that's not about us', describing how navigating the neurotypical world, managing gender role expectations and trying to fit impacts on mental health. Our third theme outlined the positive impacts of 'shedding all the layers and being myself', including the importance of formal identification, exploring autistic identity and community, and including autistic people in research to support them to 'have a good life on their own terms'.

Conclusion: This study emphasized the importance of shifting the responsibility of health and wellbeing from the individual, and the importance of interpersonal, community, cultural, policy and societal factors in ensuring positive health outcomes for autistic women and gender diverse people. It also highlighted areas that enable autistic women and gender diverse people to flourish, including autistic community connectedness, positive relationships and autistic-affirming support from health professionals.

Plain Language Summary

In this study, we wanted to understand the unique experiences of autistic women and gender diverse people. We also wanted to understand how these experiences impacted on their health and sense of wellbeing. We interviewed 31 autistic women and gender diverse people, and asked them about their experiences. We identified three main ideas or themes. The first theme is about 'all the stuff that you have to do to get through life' such as cleaning, shopping, managing finances, parenting, managing periods, menopause, pregnancy, childbirth and physical health. Our second theme

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showed the effect that everyday life has on autistic women and gender diverse people. This included being overwhelmed by navigating public spaces, fitting with expected gender roles and the impact of 'living in a world that's not about us' on mental health. The final theme highlighted the positive impacts of being autistic and connecting with other autistic people, and the importance of including autistic people in research. We discuss how our findings show the need for better interactions with healthcare professionals, access to the right services, and changing attitudes in the community and society. These changes are critical to support the positive health and wellbeing of autistic women and gender diverse people.

Keywords

adults, autism, daily living, gender diversity, health, mental health, participatory research, wellbeing, women

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Introduction

The World Health Organization (WHO) defines health as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity'.¹ This definition states that health cannot be considered without including wellbeing. Wellbeing has been defined as 'feeling good and functioning well'² and includes more than just happiness and life functioning, but also a sense of control over one's life, positive relationships, having a sense of purpose and being able to develop your potential.³ Health and wellbeing are 'fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition'.¹ This affirms the right to health and wellbeing, but does not consider that some opportunities, systems and supports, will not be appropriate for all people. This is often the case for many autistic people. Autistic people experience health inequities and are at increased risk for physical and mental health conditions,⁴⁻⁷ shorter life expectancy,⁸ experiencing violence⁹ and suicide.^{8,10} In addition, autistic women report experience more physical^{11,12} and mental health conditions^{13,14} and use healthcare more frequently¹² than autistic men. It is also important to consider the additional health inequities experienced by trans and gender diverse autistic people, given the high proportion of autistic people who report a gender identity different from their sex assigned at birth.^{15,16} Gender diverse autistic people experience higher levels of mental health difficulties compared to both cis-gender autistic people¹⁷ and non-autistic gender diverse people,¹⁸ outlining the impacts of being part of multiple marginalized groups on mental health. Autistic women and gender diverse people are also at increased risk of sexual violence¹⁹ and have additional needs related to their health and wellbeing, including sexual and reproductive health,²⁰ experiences of pregnancy and childbirth,²¹ and managing periods and menopause.²² Despite these additional needs, autistic women and gender diverse people report significantly more barriers to accessing services,²³ including stigma and a lack of knowledge from healthcare providers²⁴ and are underrepresented in research.^{25,26}

Much of the research on the health and wellbeing of autistic people has been framed within the medical model,²⁷ which uses terms such as 'deficit' or 'disorder', and sees autism as a series of impairments within an individual that require remediation. However, there are many objections to the use of this medical model,^{28,29} and it is important to move away from conceptualizing autism as something that differs from the 'norm' expected within society.³⁰ The medical model ignores the contribution of social and cultural factors in the construction of disability.³¹ In addition, research framed within the medical model has often focused on understanding causation, which results in a lack of understanding of autistic people's life experiences.³⁰ In contrast, social ecological models³²⁻³⁵ provide a framework for understanding the interrelated influences of individual, interpersonal, community, policy and societal factors on a person's health and wellbeing. This then enables a shift from the individual to being solely responsible for their health outcomes or disability, to include the responsibility of others on interpersonal, social, cultural, economic, policy and societal levels.³⁶ The health and wellbeing of autistic women and gender diverse people needs to be considered within the context of this social ecological framework, as it can provide potential explanations and solutions for the health inequities experienced by this population. This also fits with the neurodiversity paradigm, which emphasizes the need to adjust both the physical and social environment to meet the needs of autistic people.³⁰

We know that health outcomes are influenced by social and cultural norms, and everyday experiences.³⁷ Despite this, there has been little research that explores how daily life impacts the health and wellbeing of autistic women and gender diverse people. Autobiographical accounts highlight day-to-day challenges, including sensory overload and physical exhaustion.³⁸ Others have also noted 'the invisible struggle' for autistic women and gender diverse people and the impact of managing daily tasks.³⁹ There has been some research related to activities of daily living (ADLs) such as caring for oneself, personal hygiene, eating and dressing,⁴⁰ and more complex tasks or

instrumental activities of daily living (IADLs), such as grocery shopping, meal preparation, home maintenance, managing finances, health and taking care of others.^{40,41} This research has shown that autistic girls experience more challenges with daily living skills compared to autistic boys.⁴² However, this research has mostly been based on parent reports, or focused on providing training for ADL skills development, with minimal research asking autistic people themselves about their needs or experiences.⁴³ A recent study asked older autistic adults about their IADLs, highlighting that these were impacted not only by individual factors, such as sensory sensitivity and executive function, but also influenced by environmental and cultural factors.⁴⁴ There is no research to date that seeks to understand the impact of managing these daily living skills on health and wellbeing. This is particularly important for autistic women and gender diverse people, as gender roles and expectations result in additional pressure to take responsibility for, and engage in these tasks. Social and cultural factors have also been shown to be embedded in everyday experiences and play a role in the development of a sense of self for autistic women.⁴⁵ It is important to understand the everyday experiences of autistic women and gender diverse people in the context of these social and cultural factors. It is also critical to co-produce research with the autistic community to ensure that research addresses their needs. In this autistic-led study, we asked autistic women and gender diverse people for their unique perspectives and insights about their everyday experiences. We also aimed to understand how these impact on their health and wellbeing.

Methods

Participants

We interviewed 31 autistic women and gender diverse people aged 18 years and above. Full demographic and background data are available for 30 of these interviews. Our sample ranged from 21 to 63 years of age, with a mean age of 39 years ($SD=12$). Most (83%) of our sample had been diagnosed as autistic by a health professional between 3 and 55 years of age ($M=33$, $SD=13$; 88% were diagnosed in adulthood). For those who self-identified as autistic (i.e. did not have a formal diagnosis of autism), age of self-identification ranged from 21 to 49 years, with a mean of 34 years ($SD=11$). The majority (77%) were from a White European background, and all participants used spoken communication. 63% of the sample had completed a university degree and 70% were currently in paid employment. 40% of the sample were parents and 50% of parents also had autistic children. Additional demographic details are provided in Table 1. Co-occurring mental health conditions were reported by 83% of participants ($M=2$, $SD=1.8$). Co-occurring physical health conditions were also reported by 63% of the sample ($M=1.7$, $SD=1.7$)

Table 1. Demographic information ($n=31$).

	Frequency	%
Gender identity		
Female	26	83.9
Non-binary	2	6.5
Transgender	1	3.2
Autistic gender	1	3.2
Gender fluid	1	3.2
Education		
Completed high school	21	70.0
Trade/technical certificate	3	10.0
TAFE certificate or diploma	13	43.3
University degree	19	63.3
Employment		
Employed	14	46.7
Self-employed	8	26.7
Volunteer	5	16.7
Not currently working	11	36.7
Ethnicity		
Aboriginal or Torres Strait Islander	1	3.3
White European	23	76.7
White Other	3	10.0
South East Asian	1	3.3
Other	2	6.7

'Other' ethnicity includes South East Asian and Hispanic and mixed Mediterranean ancestry.

TAFE = Technical and Further Education.

(see Figure 1). However, only 27% of participants were receiving support under the National Disability Insurance Scheme (NDIS), which provides funding directly to individuals for supports and services.⁴⁶ Additional details on co-occurring conditions are provided in Table 2.

Procedure

These data form part of a larger study that asked autistic girls, women and gender diverse people about their experiences and challenges, and their priorities for research.⁴⁷ The results presented in this article are from the adult sample only. The study was advertised on social media, and through peak autism and disability organizations in Australia. Autistic people with either a formal diagnosis or who self-identified as autistic were included in the study. We included autistic people who identified as cis gender women, transgender, non-binary, gender diverse people and anyone who was socialised as, or identified as a woman. We used the term gender diverse within this project to fit with the recommendations outlined by the United Nations⁴⁸ and the Victorian Government in Australia.⁴⁹ We acknowledge that language in this space is dynamic and are always open to feedback from the community on what language is appropriate and inclusive. The sample was restricted to autistic people above the age

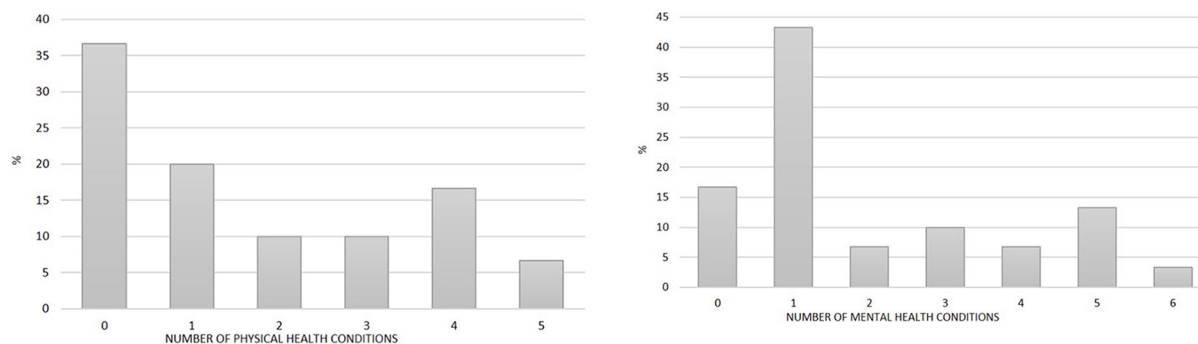


Figure 1. Co-occurring mental and physical health conditions.

Table 2. Co-occurring mental health and physical health conditions (n = 30).

	Frequency	%
Neurodivergence		
Attention-deficit hyperactivity disorder (ADHD)	8	26.7
Dyslexia	3	10.0
Dyspraxia or developmental coordination disorder	1	3.3
Other ^a	5	16.7
Mental health		
Anxiety disorder	16	53.3
Bipolar disorder ^b	3	10.0
Obsessive compulsive disorder	3	10.0
Post-traumatic stress disorder (PTSD)	9	30.0
Complex PTSD ^c	7	23.3
Depression	12	40.0
Drug or alcohol misuse	1	3.3
Dissociative identity disorder	1	3.3
Eating disorder	5	16.7
Borderline personality disorder	1	3.3
Personality disorder (not specified)	3	10.0
Physical health		
Chronic fatigue syndrome	2	6.7
Chronic pain ^d	8	26.7
Epilepsy	1	3.3
Ehlers Danlos syndrome	1	3.3
Fibromyalgia	2	6.7
Gastrointestinal issues	15	50.0
Immune conditions	3	10.0
Pernicious anaemia	1	3.3
Polycystic ovarian syndrome	4	13.3
Sleep issues	8	26.7
Thyroid problems	3	10.0
Other ^e	2	6.7

^a'Other' neurodivergence responses include Dandy–Walker syndrome, self-identified ADHD and dyspraxia, sensory processing disorder and synaesthesia.

^bN = 2 participants reported both bipolar disorder and depression.

^cN = 4 participants indicated complex PTSD (cPTSD) in conjunction with PTSD.

^dN = 2 participants reported fibromyalgia and chronic pain.

^e'Other' physical health conditions include self-identified Ehlers Danlos syndrome and acromegaly. The frequencies for each category are exactly as designated by the participants.

of 18 years currently living in Australia. Eligible participants were asked to complete a short background questionnaire that asked for demographic information, and about co-occurring conditions, employment and education. Participants were then asked to take part in a semi-structured interview over zoom, phone, email or text, depending on their preference. We asked a series of open-ended questions related to diagnosis, day-to-day experiences, support and research topics. These open-ended questions were provided to participants prior to their interview so that they could have time to reflect or prepare answers if needed. Two pilot interviews were completed with autistic advisory board members (H.C. and T.M.) prior to the initial interviews being conducted to determine suitability, structure and format of the interview questions. Interviews were conducted by an autistic woman (G.H.) and ranged from 43 to 126 min, with a mean time of 81 min (SD = 24). Interviews were video and audio recorded, and then transcribed verbatim. Transcribed interviews were sent to all participants, who were able to amend or add additional information. Regular discussion with G.H. and R.G. occurred to begin to discuss general themes and patterns across the data.

Community involvement

This project was led by an advisory board of autistic women and non-binary people (H.C., T.M. and S.G.). They were engaged in the development of the research questions and methodology, data collection, analysis, interpretation of the data and dissemination of results. This involvement included regular meetings from the outset and across the project. This was to ensure that the research was conducted in a way that was informed by lived experience, beneficial and not harmful to the autistic community, trauma-informed, person-centred and to ensure that the results are interpreted from an autistic perspective.

Data analysis

Data were analysed using Braun and Clarke's^{50,51} method for reflexive thematic analysis within an essentialist

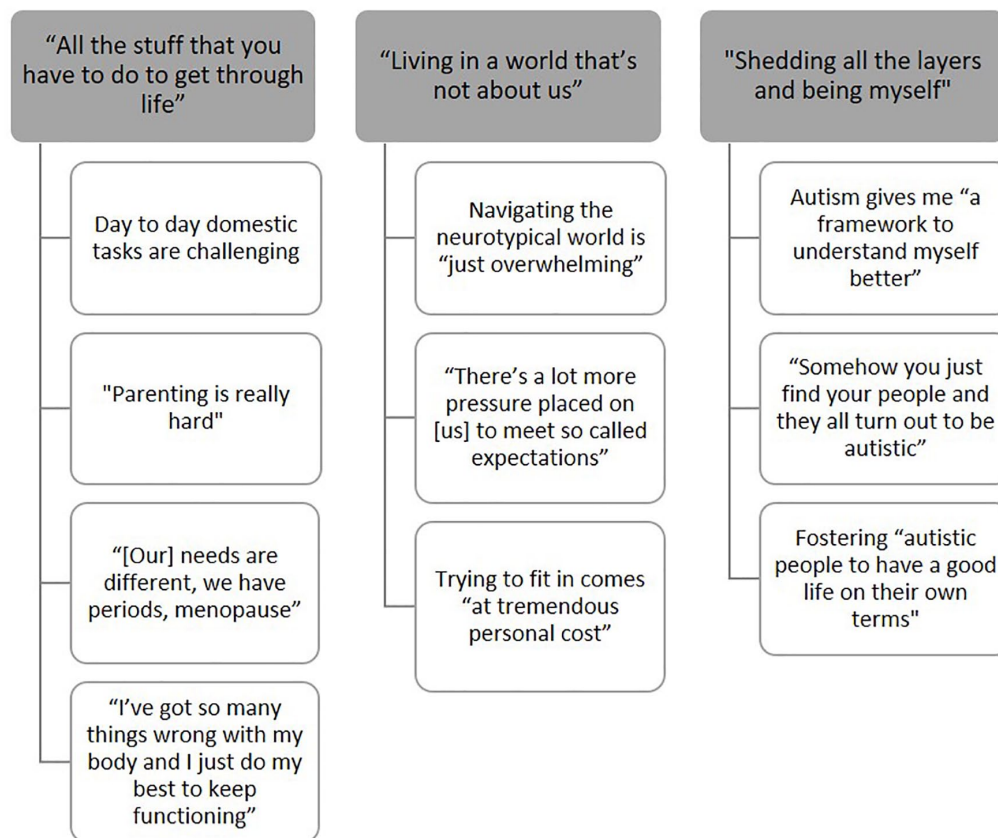


Figure 2. Thematic map.

framework, focusing on the semantic features of the data (i.e. staying close to participants' language). The data were analysed using a social ecological lens, which conceptualizes health as impacted by individual, interpersonal, community, policy and societal factors.^{32–35} This research was also conceptualized within the broader social model of disability.⁵² We identified themes using an inductive, or bottom up, approach through identifying shared patterns of meaning within the interview transcripts. Prolonged engagement with the data was undertaken by R.G., who listened to the interviews, read each transcript twice and applied initial codes to the data. Member checking with the autistic research team (H.C., T.M., S.G. and G.H.) occurred multiple times throughout the data analysis process, following which codes were further developed. Following these discussions, R.G. developed a draft thematic map, which was finalized following multiple iterations with H.C. and T.M. These processes were completed multiple times throughout the analysis and write up phase, resulting in an iterative and reflexive process to the data analysis, and ensuring the credibility and trustworthiness of the process. All authors were responsible for identifying the final themes and subthemes. Data analysis was managed with NVivo version 12.⁵³

Results

Participants described their everyday experiences and how these impacted on their health and wellbeing. We identified three themes through the reflexive process described above. These themes and subthemes are outlined in Figure 2.

Theme 1: 'All the stuff that you have to do to get through life'

Subtheme 1.1. Day-to-day domestic tasks are challenging. Autistic women and gender diverse people frequently spoke about the challenges of managing 'all the stuff that you have to do to get through life' (AD1). This included day-to-day domestic tasks, such as housework, cooking and mealtimes, and managing finances. Our participants highlighted challenges related to managing 'all the little things that fall into being your responsibility when you become an adult' (AD2) and 'trying to manage more than one thing at a time' (AD17). One participant described their experience of managing multiple domestic tasks: 'sometimes I'll go days without brushing my teeth because I haven't been able to slot that in with all the other stuff I need to do' (AD2). Additional day-to-day domestic

challenges included remembering to eat, including losing 'track of time, or I can't tell when I'm hungry enough' (AD21). Others reported that they could 'sit for eight hours and not eat anything, because I don't realise that I need to' (AD20). Challenges related to cooking and meal preparation were also reported:

so many nights over the years I've just stood in front of the fridge at five o'clock crying because I can't . . . I can't for the life of me pull together a meal . . . there's too many tasks involved. It just doesn't come naturally to me. And I've always been very ashamed of it. (AD13; 42-year-old autistic woman)

Autistic women and gender diverse people also identified challenges managing finances and 'all the day-to-day stuff. Paying bills. Paying car rego. Doing banking. Organising my life [so] that it has any sort of schedule' (AD10). Others spoke about difficulties with making phone calls due to a sense of feeling 'trapped because there's the expectation that when they talk, you will talk straight back' (AD13) or to 'accidentally speak at the wrong time' (AD31). This highlighted the lack of understanding of communication differences from others and had an impact on autonomy. These daily domestic tasks created anxiety and a tendency to 'put it off and, and then it sits there and sits there and it builds up and becomes more of a thing' (AD23). Participants described feeling that 'it's so overwhelming sometimes' and that 'someone to come and help me with the practical stuff every now and then . . . would be really beneficial' (AD20). As one autistic woman stated:

I definitely get overwhelmed quite easily and I struggle to manage the different parts of my life . . . I get quite focused on certain things, such as my work, and then don't know where to fit in things like going grocery shopping and cleaning my house. (AD20; 28-year-old autistic woman)

Executive function and sensory differences also had an impact on these domestic tasks, and although the autistic women and gender diverse people we spoke to were able to complete the day-to-day domestic tasks required, this was overwhelming and created a sense of burnout:

I theoretically know all the stuff I need to help organize and plan myself. But you can be so dysregulated that you can't do any of it. So even somebody saying, just make a list, I'm going well, I'm actually too exhausted to make the list . . . all that executive function just goes really offline when your sensory system's out. (AD14; 42-year-old autistic woman)

There were a number of strategies that the autistic women and gender diverse people we spoke to had for managing these stressors, including cooking bulk meals and having a cleaner:

I actually decided, I just wasn't coping, I didn't have enough time to do this stuff. And so I had a cleaner . . . And there

have been times where I haven't had a cleaner. Have been really, really challenging. (AD1; 50-year-old autistic woman)

Subtheme 1.2. 'Parenting is really hard'. Parenting was reported as an additional daily challenge, particularly to 'manage all of that, with the other demands that I have' (AD23) as 'things became so busy having a child' (AD1). Parenting was also related to gender roles and expectations that 'as a parent, it's my role really to put him and his needs first. And then my needs come after that' (AD23). However, autistic parents also spoke about the positive impact that their children had on their lives. For example, one parent described how being able to focus on their child made things easier:

I can't even explain it, it really helped me . . . It just simplified everything because there were no longer all these different priorities there was just the one thing that I had to do right. (AD26; 38-year-old autistic woman)

Another autistic parent described their parenting as a strength and the motivation to support their children in the way that they need:

Anything to do with my kids I'm much better at . . . I'm very highly motivated to be the best mother that I can be, and support them the best way. (AD7; 51-year-old autistic woman)

Subtheme 1.3. '[Our] needs are different, we have periods, menopause'. Sexual and reproductive health was a key area that was identified as a daily challenge by autistic women and gender diverse people. This was related to experiences of pregnancy and childbirth, puberty, periods and menopause. Childbirth was identified as having an impact on sensory processing:

Like having childbirth as an autistic person, that stuff where you want to be in a good frame of mind, and sensory, it could be an absolute trauma. (AD16; 30-year-old autistic woman)

Others also spoke about their experiences of pregnancy and how this impacted on their energy levels and ability to work. This was also associated with not being listened to or supported by health professionals during pregnancy:

Because when I was saying that I was tired, and I was sick, and I really didn't feel like I could work, I wasn't being believed. If I had known that I was on the spectrum, I could have said, well look, you know, I do my best to last the full day as it is. With this extra thing I can't . . . I could have been more realistic on myself. (AD28; 47-year-old autistic woman)

Puberty was associated with exacerbating 'mental health issues if you're susceptible to it, but more so for autistic women' (AD13) and that 'puberty and autism, well undiagnosed autism, doesn't really mix very well' (AD19).

One participant noted the significant impact that managing puberty had on their life:

Puberty was horrible. From that point on, up to my early 20s, was hell, absolute hell . . . It was pretty awful, and I remember it being a really emotional time . . . with the huge emotions. I blocked it out. (AD9; 49-year-old autistic woman).

Difficulties with the physical changes that occurred during puberty, including the ongoing challenges associated with managing periods were also reported. Period pain was described as ‘just horrific’ (AD23) and ‘so uncomfortable and it was so hard to focus on anything’ (AD2). The ‘sensory aspect of having my period each month’ (AD13), including using tampons and pads were also highlighted as part of the everyday challenges experienced by autistic women and gender diverse people. Others spoke about the empowerment they felt when they learnt ‘how things change with your cycle. And I found how that also impacts with different parts with my autism at different parts in the cycle’ (AD29). Menopause was also noted to be associated with ‘sensory processing’ challenges and ‘like going through puberty again’ (AD14). This was described as being ‘confusing for women. Because their whole body is changing. Their whole life is changing’ (AD14).

Subtheme 1.4. ‘I’ve got so many things wrong with my body. I just do my best to keep functioning’. The everyday experiences of autistic women and gender diverse people were impacted by co-occurring physical health conditions that were often described as highly debilitating. Our participants reported a long history in dealing with the healthcare system and ‘seeing specialists all of my life’ (AD1). Navigating the health system was also associated with additional challenges including managing sensory aspects, such as ‘bright lights, people running in and out’ (AD16). The autistic women and gender diverse people we interviewed also spoke about not being heard by health professionals, including having ‘presentations in my diseases that are different to typical . . . and it’s hard to get the doctors to believe that’ (AD15). This was also related to disclosing ‘to my GP . . . that I’m autistic. She’s a bit flippant . . . So she’s not someone that I would probably feel like I’d needed to tell’ (AD1). Others reported that ‘trying to get what I need out of my medical team is really hard because I can’t explain how I feel about things. And because I don’t overdramatise’ (AD15) and highlighted the impacts of a male-biased healthcare system on managing their health: ‘the medical system is patriarchal’ (AD11). This often resulted in autistic women and gender diverse people not attempting to seek care and therefore not knowing ‘exactly what conditions I have because basically I don’t go to the doctor’s ever. I just don’t go’ (AD12). There was also a sense of feeling unsupported by health professionals:

Until last year, a lot of my chronic health issues were not being treated. And I had really severe issues. I was going in and out of hospital . . . and nobody was doing any aftercare . . . I was on medication that did nothing. Nobody ever took me aside and said, this is not good enough. We need to up the ante. (AD16; 30-year-old autistic woman)

Theme 2: ‘Living in a world that’s not about us’

Subtheme 2.1. Navigating the neurotypical world is ‘just overwhelming’. Autistic women and gender diverse people spoke about challenges related to navigating the neurotypical-favoured built environment, including ‘getting to and from work’ (AD16) and catching ‘public transport or anything like that . . . I have to make sure I have an exit wherever I am . . . a bus is not [an exit] because I have to wait’ (AD19). However, others also noted challenges with driving, due to ‘over-stimulus’ (AD28) and ‘sensory overload’ (AD2). One participant described their experience of driving:

I compare it to like ice skating. Because, I can ice skate . . . But in the long run, I’m sometimes more mentally exhausted because I have to focus on balancing. People left and right. What is everyone else doing? Where am I going? And I feel like driving sounds the exact same. (AD21; 23-year-old non-binary autistic person)

Our participants also described being ‘uncomfortable to go to places I hadn’t been’ or ‘going shopping, or going to the movies or anything on my own’ (AD21). This was associated with significant sensory impacts, due to ‘taking all senses in’ (AD11) and ‘the bright lights. If there’s lots of people, the increased noise. It’s just the people. The people that you have to navigate around’ (AD1). This was related to the feelings of overwhelm and being unsafe:

I get disorientated due to sensory overload and then I’ll be like what am I doing out here? Why did I come out again? It can be just overwhelming. Probably the best thing I can think of is I just don’t feel safe. (AD30; 52-year-old autistic woman)

Another participant described their experiences of navigating the neurotypical built environment:

I think it’s the public spaces are uncomfortable . . . Not knowing what to do. What to say. Where to look. So many people. So many eyes. Accidentally making eye contact. (AD21; 23-year-old non-binary autistic person)

Subtheme 2.2. ‘There’s a lot more pressure placed on [us] to meet so-called expectations’. The autistic women and gender diverse people we interviewed highlighted the significant impact of gender roles and expectations on their lives. This included the cultural and societal message that ‘boys can be boys, but girls have to be girls. And that I think is damaging. The message that we get is damaging’

(AD22). Autistic women and gender diverse people also outlined the exhaustion associated with 'spending all of our time adapting to meet other people's needs' (AD14), including having 'to meet all these expectations of society' (AD26). This included being taken advantage of in the workplace:

I've been taken advantage of a lot . . . in a lot of situations, if somebody asks you for help your first instinct as a female is to say, sure yes, what do you need? And a lot of times . . . saying yes to some things is not the right thing to do. (AD25; 26-year-old autistic woman)

The impacts of conforming to these gender stereotypes were significant, with participants reporting the ability to 'change or adapt myself to the situation, but it's absolutely exhausting. By the end of it, I'm just finished' (AD9) and 'coming home train wrecked every night' (AD15). Fitting into these societal gender roles was also associated with having 'no clue who I was. I just knew who I was trying to be at that time, or who I should be to fit in with whatever group or whatever thing I was doing. And that's all I knew' (AD7). One participant also outlined the impact of managing the 'mental load':

There's a lot of mental and emotional lifting. You're constantly aware of other people's needs . . . It needs a lot of organisation, mental and emotional . . . what I call the 'mental load' . . . it is very great, and you can't put it down. Because other people's health and wellbeing and survival is involved . . . The mental weight of that by the end of the day, I've done a lot of lifting . . . if you couple that with pain, by the time I've cooked a meal, fed everybody and sat down, I'm done . . . I can barely move, I can barely sit, I'm struggling and in pain. It just becomes very difficult to be me. (AD22; 54-year-old autistic woman)

This highlights the significant impacts of managing these societal expectations and gender roles for autistic women and gender diverse people.

Subtheme 2.3. Trying to fit in comes 'at tremendous personal cost'. The autistic women and gender diverse people we interviewed spoke about the 'struggle with the fact that the way that I am and who I want to be doesn't fit in the world' (AD4). The impacts of this were significant, with one participant describing that 'growing up autistic in a world that's not meant for you' means that 'every autistic person has a trauma history' (AD1). The costs of 'trying to fit in when we actually can't . . . because our brains are different. We're wired completely differently' (AD30) had a profound impact on the health and wellbeing of our participants, coming 'at tremendous personal cost' (AD9). There were a number of coping mechanisms described by our participants, which had a great significant impact on their lives:

And I know how I coped. I coped because I was smoking 40 cigarettes a day and drinking ten cups of coffee, just so that my executive function was functioning at all. But I broke myself down by the age of 39 completely. (AD10; 51-year-old gender fluid autistic person)

Another participant described their experience of masking in the workplace:

Usually it's just trying to hold it all together until I can get home, and feel like I can relax, to be myself without fear of retribution or offending someone . . . Each day is different, and some days it's just surviving the day so I can get home in one piece from work. (AD27; 30-year-old autistic woman)

This was related to autistic burnout and having a 'lot of public meltdown burnout moments where I hadn't really known what was going on, and other people haven't really understood what was going on' (AD26). Others also noted that 'doing many things at the same time . . . for a long period of time, I start getting burnout' (AD24).

The everyday challenges experienced by autistic women and gender diverse people also had an impact on their mental health. These experiences were related to a sense of 'shame of who I was' through being told 'that I'm wrong. I've got to do this' (AD7). Others spoke about being 'ashamed my whole life of having Asperger's instead of going hey man that's why I'm deadly . . . because I've always felt different, I always felt like freak, I always felt that I was naughty, or a bully or that I was just considered a very bad person for a lot of things' (AD28). Trying to fit in also resulted in suicidality and self-harm due to feeling that 'existence was just too painful . . . I'd try and fit in, and then I wouldn't try and fit in, and then I'd try it and be something else. I did a lot of self-harm and a few suicide attempts in there. But it was just painful' (AD26).

Mental health was also further impacted by a lack of understanding, being dismissed or experiencing gaslighting from health professionals, resulting in a 'severe mistrust of anyone' (AD10). This often included extended periods of feeling unsupported by the mental health system:

I have had very intensive mental health support. Ongoing for majority of the past 20 years. And not once was autism ever even considered . . . Was not even suggested at all. And even after my diagnosis, my last admission to the psychiatric unit last year, when I mentioned my diagnosis, the psychiatrists in there dismissed it . . . it was written on my discharge summary, there are no outward signs of autism. (AD13; 42-year-old autistic woman)

Others also described a sense of internalized ableism and the shame that was associated with describing their challenges to health professionals:

There was the shame of who I was . . . and how. It was buried so deep . . . that it doesn't, you know, you don't just wander in and say, Look, I don't understand people, and I don't get what's going on. And I try so hard. And I can't figure out you know, you don't walk in and say that, and they're just like, no, you're fine. (AD7; 51-year-old autistic woman)

These everyday experiences also resulted in autistic women and gender diverse people needing 'to work really hard in this world to get where we are. Much harder than anyone else' (AD1). There was a sense of grief around not being 'given that chance to live life and actually succeed' (AD19) or being told you had 'huge potential, and I've never ever reached it. I've never done anything with my life . . . That hurts a lot' (AD13). This loss of potential was noted by a number of the autistic women and gender diverse people we spoke to:

I do think we're losing a lot of potential. We're losing it to mental illness, we're losing it to apathy, we're losing it to self-defensive behaviours . . . I think there is a very subtle epidemic of loss in our society of girls, who cannot reach their potential. (AD22; 54-year-old autistic woman)

Theme 3: 'Shedding all the layers and being myself'

Subtheme 3.1. Autism gives me 'a framework to understand myself better'. Autistic women and gender diverse people identified a number of things that had a positive impact on their lives. This included being formally identified or diagnosed as autistic, which was described as providing an opportunity to go 'back through your whole life through this lens of autism' (AD14) and having a 'framework to understand myself a little bit better, instead of continually falling apart and wondering, why on earth am I like this?' (AD13). Formal identification provided an opportunity for autistic women and gender diverse people to be 'released from a dialogue of moral failing. You can't do this because you're bad and lazy. You can't do that because you don't try hard enough' (AD6). It was also associated with being able to 'accept my life and myself as I am' (AD14) through being able to 'go back and reinterpret experiences . . . and then kind of put the past in the past' (AD8). The positive impact of 'being diagnosed as autistic, was then just getting to this level of understanding and shedding all the layers and being myself and being able to be happy' (AD7) was a common experience. This was also associated with being able to make positive lifestyle changes:

And I think that learning about autism at the age 41, 42 was possibly the biggest gift I could give to myself. Because I completely changed my lifestyle. The more information I received about what being autistic was for me, the more accommodations I could offer myself. (AD10; 51-year-old autistic gender fluid person)

Subtheme 3.2. 'Somehow you just find your people and they all turn out to be autistic'. Developing autistic identity and connecting with the autistic community was also reported to have a positive impact on the lives of autistic women and gender diverse people, through understanding 'that I wasn't weird. I was just autistic' (AD1). Autism was conceptualized 'as an intrinsic part of who I am' (AD23) and that 'disability is an identity, not something to be ashamed of' (AD25). Autistic women and gender diverse people also spoke about the importance of being accepted for who they are and being able to express their gender identity. There were reported experiences of gender dysphoria and how this 'feels like being burned up and hollowed out' and that embracing their gender identity alleviated this due to being 'able to fully make that switch in my mind' (AD5). One participant described their experience of gender:

Gender, I think, is a very strange thing for autistic people . . . I've gone through phases in my life where I've been really, really overtly masculine. And then I've gone through other stages in my life where I've been really overtly not masculine or really, really neutral . . . Everything is like a costume that comes with an implied gender, but actually underneath that there is no gender. It's completely irrelevant. It does not mean anything. (AD12; 49-year-old autistic gender person)

Participants who self-identified as autistic spoke about the importance of 'being able to identify with certainty, something that is very intrinsically you' and that 'we should be able to say, with some self-defining confidence, that I am autistic. This is me' (AD22). Others also indicated that formal identification would enable them to 'feel a part of a tribe' (AD23). This connection with autistic community was highlighted by the autistic women and gender diverse people that we interviewed, and that 'somehow you just find your people and then they all turn out to be autistic because they're the people that you can relate to and you get along with' (AD12). This was reported to be 'quite empowering in some ways, because it's given me opportunities to connect in with other people with autism and learn quite a lot about the autistic community, as well as myself' (AD20). The positive impact of connecting to 'my tribe' made it clear 'why I've clustered with certain people and not others' (AD26), and the benefits of this were clearly described:

I love working with and hanging out with other autistic or neurodiverse individuals. The connection and communication feels much more effortless and more natural than it does with non-autistic or non neurodiverse individuals. (AD23; 51-year-old autistic woman)

Subtheme 3.3. Fostering 'autistic people to have a good life on their own terms'. The final subtheme related to how to

foster 'autistic people to have a good life on their own terms' (AD10). This included

'having a network of caring relationships, as well as having time, each day, in small and big ways, to do my autistic passions, and having safe people around me in general, people I don't have to wear the mask as much with' (AD25).

Support for autistic people to live life as their true selves was also noted as being important for autistic women and gender diverse people:

We could be supported and still have a much greater contribution to business, to society, to economy, to knowledge . . . It just seems to be a huge loss. Not just personally, but on so many levels. That we're not supporting women and girls more. Not just so that they can procreate, but just so that they can be themselves. (AD22; 54-year-old autistic woman)

This can be achieved through 'making sure that autistic people are part of the team and are doing the research' (AD1) and for 'research on understanding it from the autistic perspective rather than layering that non-autistic perspective over the top' (AD14). The importance of autistic clinicians 'coming from an autistic perspective with lived experience' (AD23) was also identified as being paramount to supporting the health and wellbeing of autistic women and gender diverse people. Harnessing autistic strengths was also highlighted as an important aspect of this: 'they're all things that people would either try to extinguish or diminish or not have. But when you see them from a positive aspect, you can do so much with them' (AD14).

Autistic women and gender diverse people spoke about their positive experiences with health professionals, including 'someone else to come in and say, you don't need to be doing that, that's quite helpful' (AD20). Others also indicated the impact that receiving this support had on their lives, such as having a 'psychotherapist, a psychiatrist, an ADHD coach who talk to each other in an arrangement that they proposed, and so I don't have to co-ordinate that which is fantastic' (AD6). This was noted as a rare, but positive experience for some of our participants:

Well, I have been really lucky, because I stumbled across a brilliant doctor. A wonderful, wonderful man who listens. He's so present and listens and believes everything you say. He's like some kind of unicorn doctor. (AD7; 51-year-old autistic woman)

Discussion

This autistic-led study asked autistic women and gender diverse people about their everyday experiences and how these impacted on their health and wellbeing. We identified three themes, which included 'all the stuff that you have to do to get through life', the costs of 'living in a

world that's not about us' and the positive impacts of 'shedding all the layers and being myself'.

Our first theme highlighted some of the daily challenges that autistic women and gender diverse people experience, including with ADLs or self-care tasks, such as remembering to eat. In addition, IADLs such as meal preparation, shopping, home maintenance, managing finances, health, communication and parenting were identified. This is consistent with previous research outlining that autistic girls may experience more challenges with ADLs.⁴² The previous literature on ADLs and IADLs has focused on teaching skills to young autistic people, or the experiences of older autistic adults.⁴⁴ However, our research highlighted that these challenges are important to consider for autistic women and gender diverse people across the lifespan. Interestingly, the difficulties reported by our sample were not necessarily related to the capability of completing these tasks, but instead to the overwhelming nature of all the competing tasks that needed to be completed, and the associated stress and anxiety related to this. This has clinical implications, highlighting that health professionals need to be aware of the potential additional impacts of these daily domestic tasks on anxiety and stress for this population. There needs to be less emphasis on teaching social skills, as has often been the focus of support programmes, with more support provided for these everyday experiences. This includes parenting, where much of the previous research has focused on neurotypical parents of autistic children rather than autistic parents themselves. However, our findings are consistent with a recent study in which autistic parents described the challenges of being a parent, alongside those of joy in connecting with their children.⁵⁴ Our findings indicate a need for additional research that focuses on providing an in-depth understanding of autistic women and gender diverse people's experiences of parenthood and parental support, and how to best support their health and wellbeing as parents. In addition, clinical practice needs to recognize the importance of supporting autistic parents and developing parenting support programmes that meet their needs.

Autistic women and gender diverse people identified the need for research and practice to recognize that '[our] needs are different, we have periods, menopause'. The experiences of our participants were similar to those identified by previous research, including painful periods⁵⁵ and the sensory challenges related to menstruation,⁵⁶ menopause,⁵⁷ and pregnancy and childbirth.^{58,59} There is a need for health professionals to be aware of how to support the sexual and reproductive health of autistic women. This is especially important for trans and gender diverse people, with evidence showing that non-autistic trans and gender diverse people experience barriers to accessing contraception, abortion, and pre-conception and perinatal care.⁶⁰ Providing gender-affirming sexual and reproductive healthcare for autistic gender diverse people is essential

for future research and clinical practice, and is an area where there is limited knowledge and support available.²⁰

These challenges also need to be considered alongside the additional physical health needs of autistic women and gender diverse people. Our findings were consistent with previous research showing that autistic girls and women experience more physical health challenges than non-autistic women and autistic males.¹¹ The most commonly reported physical health challenges in this study included gastrointestinal issues, chronic pain and sleep difficulties. It is not surprising given the experiences reported by our participants, that they experience these health challenges, given their relationship to stress.⁶¹ While not within the scope of this study, it would be interesting to determine whether there is a direct relationship between these physical health conditions and the daily challenges experienced by autistic women and gender diverse people. This is also important for clinical practice, as health professionals need to be aware that these conditions may be more common in this population.

The second theme provided new insights into how the daily experiences of autistic women and gender diverse people impact on their health and wellbeing. Our participants outlined the costs that were associated with trying to fit into a society that does not support them. This came at ‘tremendous personal cost’ to the health and wellbeing of autistic women and gender diverse people, resulting in shame, self-harm, suicidality and mental health conditions. 83% of our participants reported one or more diagnosed mental health condition, most commonly anxiety, depression and post-traumatic stress disorder (PTSD). This is consistent with previous research outlining the increased incidence of mental health difficulties in autistic women and gender diverse people.¹³ Our participants also outlined their experiences of autistic burnout as a result of coping with the cumulative impacts of managing a lot of tasks and navigating the neurotypical built environment. This adds to the emerging literature identifying the experiences of burnout in autistic adults.⁶²

Recent research has shown that experiences of trauma and abuse are high in this population.^{63,64} This was also evident in our study, with 40% of our sample having received a diagnosis of PTSD or complex PTSD. In addition, autistic women and gender diverse people identified the impacts of ‘living in a world that’s not about us’, which were in some cases described as trauma. This fits with recent research outlining that autistic people may experience a broader range of life events as traumatic.⁶⁵ Our research highlights that the narrow diagnostic definitions of what constitute a traumatic event⁶⁶ may not always be appropriate for this population. Research and clinical practice would benefit from expanding their understanding of trauma to consider the impacts of everyday stressors related to navigating the neurotypical built environment and trying to fit with societal expectations on the health and wellbeing of autistic women and gender diverse

people. These findings also highlight the importance of providing trauma-informed care within health services.

The impact of normative cultural standards including neurotypical norms for behaviour, ableism and gender role expectations were also outlined by this research. Our findings, which indicated the additional pressures on autistic women and gender diverse people to ‘meet so-called expectations’, are consistent with the notion that society responds to, and has different expectations for autistic women compared to autistic men.^{67–70} This also has additional impacts on autistic women and gender diverse people who may not identify with typical gender roles.⁶⁸ Our research highlights how the intersection of ableism and gender inequality creates compounding challenges for autistic women and gender diverse people. This needs to be recognized and supported by clinical practice. The impact of these societal factors may provide some insight into potential reasons why autistic women and gender diverse people experience higher levels of mental health conditions, burnout and health inequities. It is helpful to frame our understanding of the health and wellbeing of autistic women and gender diverse people within the social ecological model of health (see Figure 3). Within this framework, there are opportunities to make changes on interpersonal, community, policy and societal levels to benefit autistic women and gender diverse people, and the health professionals that support them.

Previous research has identified barriers to support, including a lack of knowledge about autism in women and gender diverse people from healthcare providers,⁷¹ and a misunderstanding or disregard for their healthcare needs.⁷² We also identified additional barriers related to challenging communication and interpersonal relationships with healthcare professionals. The autistic women and gender diverse people we spoke to outlined common experiences of medical gaslighting, and not feeling comfortable enough to disclose their autism. This meant that they were not receiving the right support or had disengaged completely. This is consistent with the experiences outlined by other autistic adults^{73,74} and highlights the need to further understand why these experiences are so common. This may be due to a lack of knowledge and training,^{75–77} and reduced confidence of general practitioners (GPs) in supporting autistic people.⁷⁸ It is critical to upskill GPs and other health professionals to be able to support autistic women and gender diverse people’s healthcare needs. There is also a need to support autistic clinicians⁷⁹ and provide gender-affirming care that is appropriate for the LGBTQIA+ and gender diverse autistic community.

There are also important policy changes that need to be considered, with only 27% of our sample having an NDIS plan. While healthcare is free under Medicare in Australia, access to additional supports is not always funded under this scheme. The NDIS provides individual funding for support and services but is subject to an application process in which individuals have to prove their level of disability, resulting in ‘constantly being denied supports

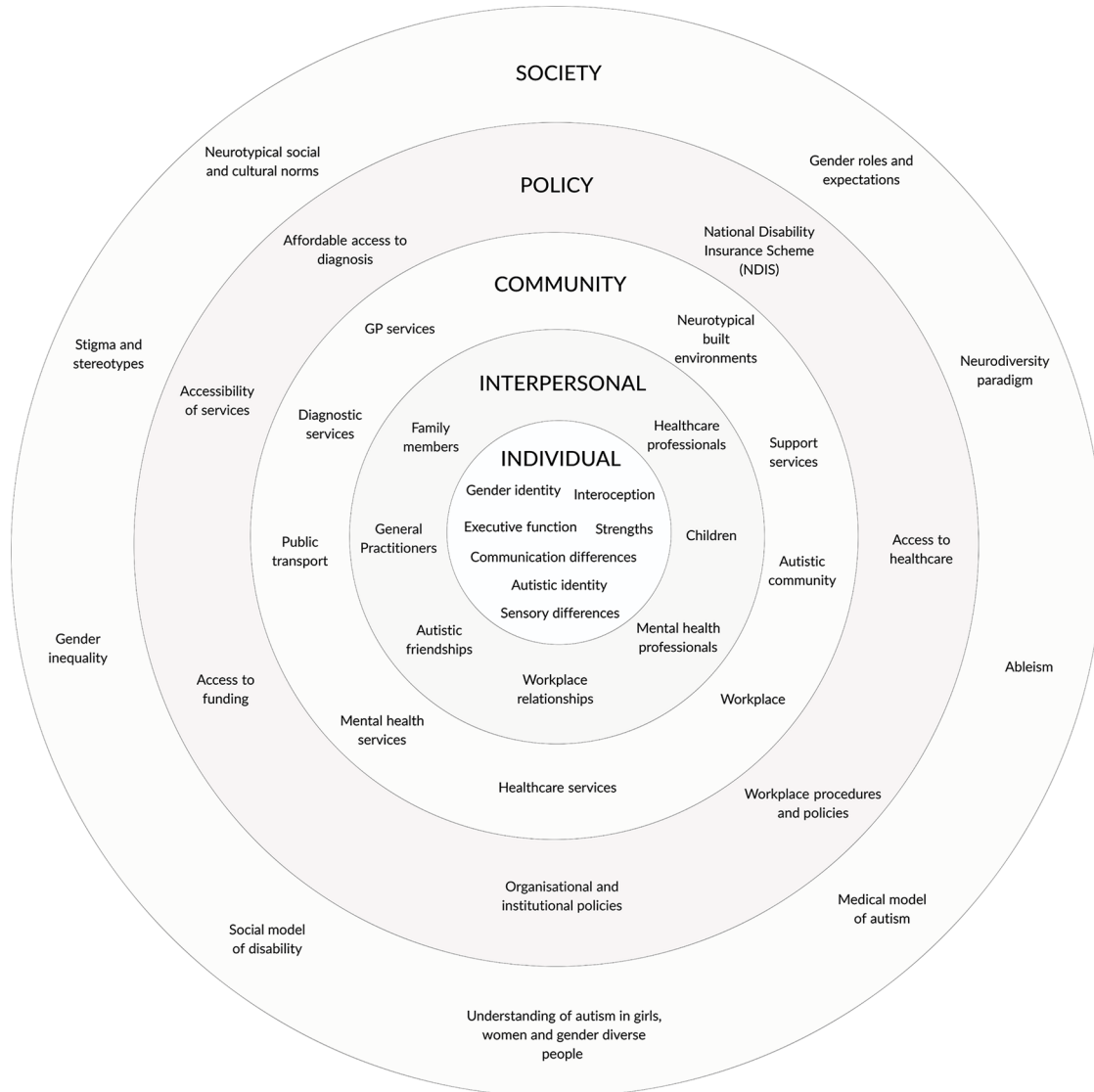


Figure 3. Social ecological model.

Source: Adapted from McLeroy et al.³⁵ by Tasha Golden.⁸⁰

This model only includes factors that were identified in our study. We acknowledge that there are other interpersonal, community, policy and societal factors that contribute to the health and wellbeing of autistic women and gender diverse people.

because it appears I don't really need them' (AD27). Our findings reveal a mismatch between the level of 'functioning' identified by diagnostic criteria and the level of daily support required. This has significant clinical implications, as it highlights the 'invisible' challenges that autistic women and gender diverse people experience, that are not being accounted for as part of the diagnostic process. This indicates a need for a more wholistic approach to providing assessment, diagnosis and support for autistic women and gender diverse people.

Part of providing this wholistic approach includes understanding the strengths of autistic women and gender diverse people, and the things that can have a positive impact and support 'autistic people to have a good life on their own terms' (AD10). Autistic women and gender

diverse people outlined the importance of autistic identity, community and self-acceptance for their health and wellbeing. Our findings also highlighted that autism provided 'a framework to understand myself better' and provided a lens through which to review past experiences and come to a level of self-acceptance. This fits with previous research showing a relationship between autistic identity and mental health,^{4,81-83} and the importance of diagnosis.⁸⁴ Our research also outlined the impact of positive interpersonal relationships with other autistic people and access to autistic community. This is consistent with previous research that shows that autistic community connectedness is related to a sense of belonging⁸⁵ and enhanced wellbeing.⁸⁶ The benefits of 'shedding all the layers and being myself' on the health and wellbeing of autistic women and

gender diverse people outlines the need for strategies within clinical practice to support the development of a positive autistic identity and access to autistic community.

One of the ways to ensure that we are supporting the needs of autistic women and gender diverse people is to include autistic people in research related to their health and wellbeing.⁸⁷ Research has traditionally ignored the voices of autistic people, but there is an increasing focus on community-driven research, and research conducted by autistic academics.⁸⁸ It is also important for future research to look at autistic identity through an intersectional lens,⁸⁹ to ensure that the needs of all autistic people are supported. Future research should also focus on developing autistic-led models of wellbeing, as traditional models have focused on areas that are valued by society, such as employment or participation in society. This is consistent with understanding autism from the neurodiversity paradigm, which outlines that an autistic person's life should be fulfilling despite not fitting with conventional norms or societal expectations.^{30,90}

Limitations

Our sample included autistic people who use spoken communication, were well educated, employed, diagnosed later in life and predominantly from a White European background. Future research needs to include people from diverse backgrounds, including people with intellectual disability, non-speaking autistic people, and autistic women and gender diverse people from different cultural backgrounds, particularly those in non-Western countries. It is also important to interrogate the culture of research to understand why these populations are still underrepresented in research. In addition, research focusing on a larger sample of gender diverse autistic people would potentially highlight further areas of need related to their health and wellbeing.

Conclusion

This study explored the unique daily experiences of autistic women and gender diverse people and how they impact on health and wellbeing. It provides new insights into potential factors that may contribute to the higher incidence of mental health conditions and burnout experienced by this population. It emphasizes the need to understand these experiences from a social ecological framework and the interpersonal, community, policy and societal factors that contribute to the health inequities experienced by autistic women and gender diverse people in Australia. It is important to address health inequities across all levels of this framework rather than focusing on individual factors and expecting autistic people to meet neurotypical norms. We need to start by understanding the daily needs of autistic women and gender diverse people, and how we can support and fund them appropriately, including their needs related

to ADL and IADLs. Fostering positive interpersonal relationships with health professionals, and upskilling the profession to recognize and support the physical, mental, sexual and reproductive health needs of autistic women and gender diverse people is critical. It is also crucial to address stigma, ableism, built environments and gender role expectations within society and in policy development. We also need to approach mental and physical health in a more holistic way to consider everyday experiences and their impact on the health and wellbeing of autistic women and gender diverse people. This includes a paradigm shift to move beyond expecting an autistic person to try to fit an ableist normative mould, to thinking about how to support autistic people to live a good life on their own terms.

Declarations

Ethics approval and consent to participate

Ethical approval was received from the Human Research Ethics Committees of the University of Technology Sydney (UTS) on 10 March 2020: UTS HREC REF NO-ETH19-4538. Written informed consent was obtained from all participants after they had received a complete description of the study.

Consent for publication

Informed consent for publication was provided by all participants.

Author contribution(s)

Rachel Grove: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Writing – original draft; Writing – review & editing.

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Tess Moodie: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Writing – original draft; Writing – review & editing.

Sarah Gurrin: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Writing – review & editing.

Gabrielle Hall: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing.

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Availability of data and materials

Due to the sensitive nature of the data, it is not able to be made available.

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