Examining the support experiences of autistic young people with multiple marginalized identities in the United Kingdom

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Community Brief

Why is this an important issue?

Autistic people are a marginalized group in society. Accessing support – and especially the 'right' support – can be hard for autistic young people. This experience might be particularly difficult for autistic young people who belong to more than one marginalized group (what we call having 'multiple marginalized identities'). For example, an autistic person who is also part of a minority ethnic group might face additional barriers to getting the support they need, compared to an autistic person who is not part of a minority ethnic group.

What was the purpose of this study?

We wanted to understand how we can make sure support reaches autistic young people from as many different backgrounds as possible.

What did the researchers do?

Our team of autistic and non-autistic researchers interviewed 13 autistic young people (aged 16 to 25 years) who had multiple marginalized identities. We asked them about their experiences of trying to get support. We read through the interviews as a team and grouped similar responses together.

What were the results of the study?

Our participants felt that it was hard for all autistic people to get support, but that it might be especially hard for autistic young people with multiple marginalized identities to get support. For example, our participants told us that it took a particularly long time for them to get their diagnosis, which made it hard to get support. When they looked for support, they felt that there were no services made for people like them. Further, their parents and other people around them did not always know how to help them get support because of cultural and langauge barriers.

What are potential weaknesses in the study?

We found participants through autism charities, which means that we might have missed those who do not access any support at all. We also could not look at all the possible ways that different parts of people's identities might be marginalized. For example, we were unable to recruit anybody who had been in care or anybody with intellectual disabilities. Future research should try to explore these areas more, to better understand the challenges a wider group of autistic people face.

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

Our findings help to identify ways to make support more accessible to a wider group of autistic young people. For example, we think that it is important to offer different types of support (such as individual and group support, or face-to-face and online support) so that there are options that suit a broader range of autistic people. Our team thinks it is important for support services to make particular efforts to be inclusive, accessible and welcoming to a wide range of people. We also think autistic people need to be supported to speak up for what they need, particularly if they do not have a parent or other advocate that is able to do this for them. If these recommendations are followed, we think that a broader range of autistic young people will be able to access support where needed.

Abstract

Background: The challenges that autistic young people face when accessing support have been well-documented. However, such issues may be exacerbated for autistic young people who have additional marginalized identities (e.g., being from a minority ethnic group or minority gender) compared to autistic young people who do not have additional marginalized identities.

Methods: We took a participatory approach that included autistic young people with multiple marginalized identities at every stage of the research process. Our team interviewed 13 autistic young people (aged 16 – 25 years) who also identified with other marginalized identities. We analyzed the data using reflexive thematic analysis.

Results: We generated one superordinate theme, which reflected how accessing support was perceived to be challenging for all autistic young people, but especially so for this group with multiple marginalized identities. Within the superordinate theme, we generated three sub-themes that provide examples of how common challenges were felt to be exacerbated for our participants. First, our participants reported difficulties in obtaining timely diagnoses, which hindered access to appropriate support services. Second, they expressed a sense of exclusion from existing support structures, with services often failing to address their unique needs. Finally, cultural and linguistic barriers meant that our participants' parents and caregivers did not always know how to help them get support. As a result, some of our participants had to advocate for themselves.

Conclusion: Our findings highlight the need for more inclusive and accessible support services that meet the diverse needs of all autistic young people, including those with multiple marginalized identities. Recommendations include offering a variety of support options to accommodate individual preferences and providing ways to empower all autistic people to advocate for their support needs.

Background

Though characterized by common features, such as differences in social communication and interaction, as well as characteristic behaviors, interests and activities, autism represents a broad and heterogeneous diagnostic category.[1,2] Despite this diversity, autism research often centers on a narrow representation of autistic people: that of White, cis-gender, middle-class, heterosexual males.[3–6] This limited focus overlooks the diverse experiences within the autistic community. Intersectionality provides a valuable framework for understanding these diverse experiences. Intersectionality considers how different forms of privilege and oppression – such as those based on race, ethnicity, gender, sexuality, disability status, and socioeconomic status – intersect and compound to create unique dynamics of (dis)advantage, particularly in relation to power structures.[7] Importantly, intersectionality emphasizes how identity categories merge to co-construct one another, creating systemic inequalities that cannot be understood by examining each category in isolation.[7] As such, intersectionality offers a crucial opportunity to examine the complex social and political disadvantages autistic people face, especially those who face a "double-disadvantage" or exist within an "interlocking prison" of multiple forms of marginalization.[8,9]

Multiple Marginalization

Marginalization refers to the processes through which certain groups are pushed to the periphery of society, and therefore experience reduced access to resources, opportunities, and power.[10,11] Societal misconceptions about autism, which are often shaped by media representations and outdated stereotypes,[18,19] are likely to create barriers to social inclusion, employment, and equitable healthcare access, thus contributing to the marginalization of autistic people. As already outlined, however, some autistic people will experience additional forms of marginalization. For example, an autistic person who is part of a minority ethnic group may experience marginalization based both on their neurodivergence *and* their ethnicity, compounding the challenges they face. Indeed, review studies of research across the globe highlight unique barriers to accessing a diagnosis and support for various groups within the autistic community that face additional forms of marginalization, including women and girls,[20] those from racial and ethnic minority groups,[21] those from immigrant families,[22] those from low-socio-economic backgrounds,[23] and those with other neurodevelopmental diagnoses.[24] The cumulative effect of these intersecting barriers are likely to exacerbate the inequalities autistic people face in accessing both a diagnosis and subsequent support.[25]

Such structural inequalities and systemic barriers may also have implications for identity formation and self-perception. Indeed, the experience of marginalization not only affects day-to-day experiences but can also shape how people view themselves and their place in society.[26] According to social identity theory, people derive a sense of self-worth and identity from their membership in social groups.[27] Yet, this process is likely to be complex and challenging for autistic people with multiple marginalized identities. For example, one's marginalized identities may intersect in ways that appear incongruent, creating internal conflicts and influencing the development (or non-development) of an autistic identity. Autistic people from cultures that view autism negatively may be reluctant to embed being autistic as part of their identity through fear of stigmatization and exclusion.[28] This outcome may lead to 'continuous marginalization' whereby people find themselves excluded from all communities, as a result of their multiple identities.[29] Indeed, a recent study on the intersection of being LGBTQ+ and autistic, found that participants felt more isolated as a result of their intersecting identities. As one participant explained: "*if you have multiple identities, then it's very difficult to find people who understand and accept you*".[30(p103)] In contrast, a systematic review of 20 studies examining autistic identity concluded that external acceptance and support are crucial for the development of a positive autistic identity.[31] As a result, autistic people with multiple marginalized identities may experience a more complicated journey to forming a positive sense of self.

The Marginalization of Autistic People in the United Kingdom

In the United Kingdom (UK), marginalization occurs within a broader context of increasing societal challenges. The Joseph Rowntree Foundation (2024)[12] reports that 22% of the UK population now live in poverty, a stark indicator of growing inequality. Over a decade of austerity measures have led to significant cuts in public services, and the impact on autism services has been vast. For example, despite its universal coverage, the National Health Service (NHS) struggles with considerable waiting lists for autism assessments,[13] making accessing an autism diagnosis challenging for many autistic people and their families.[14–16] This systemic under-resourcing is likely to disproportionately affect those from lower socioeconomic backgrounds who do not possess the financial resources to seek private alternatives. These disparities extend beyond diagnosis to post-diagnostic support, which has become increasingly scarce and unevenly distributed within the current landscape. This has resulted in what is often termed a 'postcode lottery' for support, where the quality and availability of support services varies dramatically based on geographical location.

Approaches to Support for Autistic People with Multiple Marginalized Identities

The outlined challenges that autistic people with multiple marginalized identities are likely to face highlight the critical need to ensure access to the right support. Two approaches may be useful in this regard: (1) universal inclusive support, and (2) demographically targeted support. Universal approaches aim to create accessible environments and services for all autistic people. This approach seeks to eliminate barriers and promote inclusivity, ensuring that all autistic people, regardless of their background, can access the support they need. In contrast, targeted approaches focus on developing interventions for particular sub-groups of autistic people. For example, parents and educators of autistic children from the Somali and Māori communities have identified a need for more tailored support that aligns with their cultural and religious values and practices.[32,33] Such targeted interventions have shown potential success. For example, Pearson and Meadan (2021)[34] developed and evaluated an advocacy intervention for Black families raising autistic children in the United States. The intervention was found to strengthen parents' advocacy, sense of empowerment, and community support, and was translated in a different state with similarly promising results.[35]

Both universal and targeted approaches have merits and limitations in addressing the needs of multiply marginalized populations. While universal support promotes inclusivity and reduces the risk of overlooking individuals who may not fit neatly into predefined categories, it may lack the specificity needed to address more specific challenges. Targeted support offers this more specific assistance but may inadvertently exclude people who do not precisely fit into defined sub-groups and may be resource-intensive to implement across all possible identity intersections. Moreover, for autistic people with multiple marginalized identities, specialized support poses the additional challenge of prioritizing which aspects of identity to address, potentially leading to incomplete support or difficult trade-offs.

In this study, we were commissioned by the UK autism research charity Ambitious about Autism to understand whether their new post-diagnostic support program – *Understanding You, Discovering You*[36,37] – could be made maximally inclusive, or whether there was a need for targeted adaptations. To do this, we adopted a participatory approach, aiming to understand the support experiences of autistic young people with multiple marginalized identities, through working *with* autistic young people with multiple marginalized identities. To inform this goal, our specific research questions were: (a) Do autistic young people with multiple marginalized identities feel able to access support, and does this support meet their needs? (b) If/how does having multiple marginalized identities impact autistic young people's experiences of accessing and receiving support? and (c) What (if anything) would make autistic young people with multiple marginalized identities feel able to access *Understanding You, Discovering You*?

Our decision to recruit a heterogenous group of participants is rooted in the recognition that existing research inadequately represents the diverse landscape of autistic experiences. Many studies on post-diagnostic support for autistic people lack demographic information or focus on single marginalized groups (e.g., Somali communities).[33] While valuable, this approach may not capture the full complexity of experiences for autistic people with multiple marginalized identities. By embracing a diverse cohort, our study seeks to amplify the voices of those often underrepresented in autism research. This approach provides a more comprehensive understanding of the challenges faced by autistic people with multiple marginalized identities, both within the UK context and beyond.

Method

Community Involvement Statement

This research was a collaboration between a team of academic researchers based in UK universities, and a team of community researchers from the charity Ambitious about Autism. The academic team comprised four non-autistic autism researchers (JD, KC, WM and LC). The team at Ambitious about Autism comprised two autistic young people (LI & SC) who identified as having multiple marginalized identities, including coming from a minority ethnic background, having a minority faith/religion, living in a rural area, coming from a single-parent family and/or living in a low-income household, as well as a non-autistic professional at Ambitious about Autism (BR) who supported the co-development and piloting of the *Understanding You, Discovering You* program. LI, SC and BR drew on their personal and professional experiences of post-diagnostic support, while JD drew on her research expertise to guide and support the research process, with support from KC, WM and LC.

JD and LC developed an initial research proposal and provisional research questions to address a research need identified by Ambitious about Autism, and inform the ongoing development of the *Understanding You, Discovering You* program.[36,37] While the overall aim of the research and research questions were predetermined, the team collaborated at all other stages of the research process. For example, JD and LC met with LI, SC and BR regularly (via Zoom) to jointly make decisions regarding (1) the research methodology and approach (e.g., choosing to conduct individual interviews); (2) the recruitment strategy and materials; (3) broader study materials (e.g., participant information sheet and consent form, demographic questionnaire, interview guide); (3) the analysis plan; (4) the findings and implications of the research, and (5) how the findings should be disseminated. Both academic and community researchers were involved in collecting, analyzing, and interpreting the data, as well as drafting the manuscript for publication.

As LI and SC did not have existing research experience, JD and LC (with support from BR) provided training and support to ensure they felt confident in their involvement at each stage. First, JD and LC provided a 90-minute interactive training session on conducting semi-structured interviews, adapted from LC's existing teaching materials (for university students taking a research design and methodology course). The session covered general interviewing principles and if/how these might be adapted for autistic participants, information on how to build rapport with participants, and discussion of ethical considerations during interviews (e.g., protecting researchers and participants from potential harm/distress). During the interview training session, we also reviewed our interview guide, considering possible responses and discussing how to handle different potential situations ethically and sensitively. Following the session, LI and SC were offered the opportunity to read an interview transcript, practice conducting an interview with another member of the team, and/or shadow an interview, to help familiarize themselves with the process and build confidence. When LI and SC indicated they were ready, they led interviews with participants, with JD present to provide technical support (e.g., facilitating the recording) as well as providing more practical support with the interview, if needed.

When all interviews had been conducted, JD provided a 90-minute interactive training session on reflexive thematic analysis. The session included background information regarding the aims of reflexive thematic analysis,[38–40] as well as a step-by-step breakdown – with examples from other projects – of the six stages of undertaking a thematic analysis. During this session, we began to code an interview transcript from this project together. Following the training, SI and LC each coded a subset of the transcripts, with JD available over email and/or video call to provide guidance and support.

In line with good practice for autistic community involvement in research, LI and SC were financially compensated for their involvement in the project.[41] In the following sections of the paper, we describe the decisions that were made collectively, as a team, to shape our research project.

Participants

In line with the charity's broader work on supporting autistic young people, we focused on autistic people between the ages of 16 and 25 years. In line with the specific aims of this study, we determined a set of example characteristics that we felt might result in autistic young people being marginalized, and therefore underserved by existing post-diagnostic support programs. These characteristics included (1) living in a rural area; (2) being from a non-White ethnic group; (3) having a minority faith/religion; (4) living in a low-income household; (5) being a care-leaver or estranged from parents/carers; (6) coming from a single-parent family; (7) coming from an immigrant family; (8) being a minority gender (e.g., non-binary, gender diverse); (9) being LGBTQ+, and (10) having a co-occurring disability. Participants were also able to include information about other aspects of their background they felt resulted in marginalization if they wanted to.

The research was advertised via three UK charities (Ambitious about Autism, the National Autistic Society, and Autistica), and through personal contacts of the research team, between June and August 2023. In total, 54 autistic young people registered their interest in taking part and provided information about their background characteristics. We used maximum variation sampling to invite 21 participants with varied backgrounds to take part in an interview about their experiences. Despite sending two follow-ups in the weeks following the original invitation, eight of the 21 participants who were invited to take part did not coordinate a meeting. As such, only 13 autistic young people completed an interview. As a team, we considered inviting additional participants to take part, but initial reviews of the data led to the conclusion that similar messages were coming from the existing participants and that collecting additional data was unnecessary.

Of the 13 participants that took part, 12 had a formal autism diagnosis, and one was awaiting an assessment. We included the latter participant given the documented inequalities in access to a diagnosis, especially for groups represented in our target sample.[21–24] On average, those formally diagnosed received their diagnoses when they were aged 17 (SD = 2.84, range = 13 – 22 years). Over half of the participants identified as female (*n* = 8, 61.5%). Participants from the South of England – including the South East, the South West, and London – were overrepresented (*n* = 8, 61.5%). All participants reported more than one of the stated marginalized identities (average = 3.6; range = 2 – 6). Most commonly, participants were from a low-income household (*n* = 11, 84.6%), LGBTQ+ (*n* = 8, 61.5%) and/or had a co-occurring disability (*n* = 6, 46.2%). See Table 1 for participant characteristics. Note, participant characteristics are aggregated, for the protection of participants (as per our Research Ethics Committee approval).

[Insert Table 1 about here]

Materials

First, participants were asked to complete a short questionnaire, hosted on the software platform Qualtrics. The questionnaire comprised questions about participants' background characteristics, such as their age, gender identity, ethnicity, geographical location, diagnostic information, and previous experience of post-diagnostic support groups or programs. Participants were then invited to participate in a semi-structured interview in a format of their choice. Most interviews were conducted synchronously via video call (*n* = 8, 61.5%) or voice call (*n* = 1, 7.7%). The remaining four participants (30.8%) chose to take part asynchronously using a detailed questionnaire, with follow-up questions via email.

Synchronous and asynchronous interviews followed the same structure (see Supplementary Materials A). Interviews began with a rapport-building phase, with the interviewer introducing themselves and what the research was about, before outlining the structure of the interview. The remainder of the interview was guided by three key topics. In Section 1, participants were asked about themselves and their diagnosis, prompting for information about when and how they found out they were autistic, and how they felt during this time. Section 2 focused on the participants' previous experiences with support, including how they found out about the support available, what kind of support they received, and their perceptions of the good and/or not so good aspects of the support available. Participants were explicitly asked how support could be made better, and how the advertising of potential support could be improved. Section 3 centered on the participants' perceptions of how future support can be made more accessible to autistic young people with multiple marginalized identities. Specifically, we asked questions about (1) what support should involve (e.g., what topics should be covered, if/how support should be tailored for different groups); (2) how it should be structured (e.g., online vs. in person), and (3) how it should be advertised, to ensure it is inclusive and accessible to a wide range of autistic young people from different backgrounds. The interviews concluded by providing participants with an opportunity to provide additional information and/or ask questions about the research. On average, the audio-recorded interviews lasted 29 minutes (SD = 05:34, range 16:41 – 34:20), excluding the rapport-building phase and debrief. The mean interview duration is consistent with similar studies involving autistic people of this age group[42,43] and did not impact on the quality or depth of interviews.

Procedure

We gained ethical approval from the Research Ethics Committee at IOE, UCL's Faculty of Education and Society (REC1806). All participants provided informed consent to take part. Semi-structured interviews were conducted by JD, LI, and/or SC. With participants' consent, interviews were digitally recorded using Zoom or Microsoft Teams, and were automatically transcribed. Transcripts were corrected and anonymized by JD. All participants were offered a £20 voucher following their participation.

Data Analysis

JD led the analysis with support from LI and SC. Data were analyzed using reflexive thematic analysis, within a critical realist framework.[38–40] The critical realist approach acknowledges that while there is a real, objective experience of being an autistic person with multiple marginalized identities, each individual's understanding of this reality will inevitably be unique, shaped by their own social, cultural and personal factors. This framework is particularly valuable when examining multiple marginalized identities, as it allows us to recognize the complex interplay between different aspects of identity and how they collectively shape lived experiences, while also acknowledging the broader social structures and power dynamics that influence these experiences.

The analysis process (see Table 2) involved the three authors familiarizing themselves with the data through conducting the interviews and/or reading and re-reading the transcripts. We generated preliminary codes inductively and identified both semantic and latent meanings within the data.[28] While we asked specific questions about experiences related to having multiple marginalized identities, participants commonly spoke about the more general, well-documented barriers that autistic people (without other marginalized identities) face in accessing support. Given the frequency of these comments, we chose to code all data, regardless of whether it was explicitly related to having multiple marginalized identities or not. This approach allowed us to identify areas of convergence and divergence between the experiences participants perceived as being common among autistic young people generally versus experiences that participants perceived as being specific to those with multiple marginalized identities. When coding each transcript, the participant's individual background and context were considered and reflected in the codes generated, allowing us to capture how different intersecting identities may result in different experiences. For example, several participants discussed the relative representation of each of their marginalized identities. By specifying the participant's individual characteristics within codes (e.g., '*perception that LGBTQ+ is well-represented in support groups*' versus '*perceived lack of representation of non-White people within support groups*') we were able to identify differences in experiences of people with different intersecting identities.

When all transcripts had been coded, JD, LB, and SC met to discuss codes and generated three preliminary themes. The three authors met with BR and LC to discuss the preliminary themes, and the potential implications of the findings for future research and practice. At this stage, the decision was made to subsume the three preliminary themes under one overarching theme, named 'the journey to getting support is hard, but it's especially hard for us'. Following the meeting, JD wrote up a draft of the findings which was reviewed by all authors. Based on the feedback from other authors at this stage, minor adjustments were made (e.g., the subtheme 'the importance of advocacy' was renamed 'unequal access to a key champion'). When all authors agreed upon the findings, LI and SC chose a series of quotations to be included in the results section, and JD finalized the results.

[Insert Table 2 about here]

Positionality

As previously outlined, this research was undertaken by a team of autistic and non-autistic researchers. Our autistic researchers were in the same age group as our target population, and identified as having additional marginalized identities (e.g., coming from a minority ethnic background, having a minority faith, living in a rural area, coming from a single-parent family and/or living in a low-income household). Perhaps unsurprisingly, our autistic researchers found that many of their own experiences were mirrored in the stories shared by participants. Some of the non-autistic researchers also identified with one or more of the additional marginalized identities (e.g., living in a household with a low income during the target age, coming from a single-parent family, identifying as LGBTQ+). The non-autistic researchers on the team represent a range of career stages and research expertise. Two of the non-autistic researchers (KC & WM) are also clinical psychologists who are experienced in working with autistic young people in mental health settings. The team's diverse backgrounds, experiences, and expertise allowed for a nuanced and comprehensive interpretation of the research findings, and their implications for future research and practice.

Results

Participants often discussed the more general challenges that autistic people, with or without other marginalized identities, faced in accessing support. This observation was despite participants being asked specific questions about experiences related to having multiple marginalized identities. However, there were also several ways in which participants felt these challenges were exacerbated for autistic people with multiple marginalized identities. Reflecting this sentiment, we generated one overarching theme: **the journey to getting support is hard, but it's especially hard for us**. Within this theme, we discuss the ways in which accessing support was perceived to be challenging for autistic young people, marked by a sense of being let down at each stage of the diagnostic and post-diagnostic journey. We then discuss three subthemes, which provide specific examples of how these challenges were felt to be exacerbated for autistic young people with multiple marginalized identities: (1) delayed access to a diagnosis; (2) difficulties in finding the right support, and (3) unequal access to a key 'champion'.

The journey to getting support is hard, but it's especially hard for us

Our participants spoke about the range of ways in which accessing support was challenging. For example, support was often perceived to be targeted at young children and/or parents of autistic children, leaving few resources for autistic people of their age: "*most of the organizations are for children rather than adults, which is what's difficult, because your challenges don't end as soon as you're an adult*" (Participant 10; henceforth, P10). Consequently, the anticipation of their diagnosis serving as a gateway to support was felt to be far from the reality they encountered: "*[the diagnosis is] kind of underwhelming because you think like, well, I'll get the autism diagnosis and then I can get support for it. But there isn't really much support out there…you just get a label and that's it*" (P06). Where support services *were* available, they were often oversubscribed or had long waiting lists, rendering them inaccessible: "*I needed to fill out an application form [with] details that I didn't have … so I had to … chase that up. By the time I did that, they didn't have any spaces in the support group*" (P04). Similarly, funding constraints were perceived to result in a fragmented landscape of service providers: "*one support I received was a community group … [which] helped me understand that I was not alone in the way I feel and behave. However, this had to close one year later due to funding issues*" (P11); and participants discussed how they often found themselves needing to 'fight' to access these services: "*I have had to work to find autism services in my local area*" (P13).

The apparent absence of post-diagnostic support was described as impinging on participants' sense of identity and understanding of autism. Indeed, some participants struggled to reconcile their experiences with their newly acquired diagnosis without access to guidance and resources: "*There's been very much the feeling of being lost and having to live in this new identity*" (P03). The absence of support had a significant impact on participants' well-being ("*The lack of support was so poor that I have been in crisis multiple times over the years*"; P13) and raised fundamental questions about the value of the diagnosis, with some participants questioning the utility of the diagnostic process if it did not lead to the provision of meaningful support:

> *[They] identified that I struggle with speech and language. So then why didn't [they] offer SALT [speech and language therapy] to me? [They] said that I struggle with sensory issues, so why haven't I seen, like, an occupational therapist? I kind of felt like what's the point then of giving the diagnosis?* (P02)

In the absence of formal support structures, our participants discussed turning to informal online communities, which were described as valuable sources of information, education, and peer support: "*I am active in online autism groups, mostly on Facebook, and hear of some [support] through there*" (P13). Parents and educators were also seen as pivotal in ensuring access to adequate support. For example, educational institutions were described as playing a significant role in identifying potential developmental concerns and providing practical adjustments and support (e.g., "*once I started studying at university, I accessed support regarding being autistic … the support provided has helped me greatly and getting through the year would have been much tougher without it*"; P05), while parents often served as advocates in seeking assessments and subsequent support:

> *My mum called whoever is in charge of the waiting list and [explained that I] couldn't access any support because I didn't have a diagnosis … [when] they didn't do anything, my mum filed a complaint [and] … they pushed my autism diagnosis forward.* (P02)

As the transition into adulthood approached, however, participants reported a perceived need to assume more responsibility over their own lives, and access to support: "*Now I'm getting older, like I'm nearly 18, it's usually me that does research [about support]*" (P02). Yet, some participants did not feel ready to assume all responsibility, and expressed concerns about the 'cliff edge' they would face at 25 years old:

> *I'm nearly 25. And I'm realizing I'm going to have nothing … I don't feel like I'm old, I don't feel like an adult, I can't function still … I'm still living at home. I can't drive still, I find life really stressful, I'm not independent. I need support still.* (P01)

The findings outlined above highlight the broad challenges that autistic young people face in accessing support following their autism diagnosis. Yet, our participants perceived such challenges to be exacerbated as a result of their multiple marginalized identities. Next, we outline three key subthemes that provide examples of participants being further disadvantaged as a result of their intersecting identities.

Subtheme 1: Delayed Access to a Diagnosis

For many of our participants, the journey to receiving an autism diagnosis was characterized by lengthy waiting lists and diagnostic assessments ("*it was a long, drawn-out process*"; P03) which left them feeling exhausted and disheartened. Such delays were felt to be exacerbated by their multiple marginalized identities. Some participants felt they faced cultural barriers to accessing a diagnosis. For example, one participant explained: "*My mum … comes from the Philippines, and in the Philippines mental health is taboo, people have never heard of autism … I think many people are diagnosed later, simply because parents didn't know how to recognize the signs"* (P10). These delays were often felt to be compounded by widespread misconceptions and stigmatization surrounding their multiple marginalized identities. This experience resulted in a lack of recognition across various contexts, including educational and healthcare settings. As one participant noted: "*I was diagnosed with dyslexia [first]. Before that, [my difficulties* *were] blamed on being a young carer, being around adults all the time, because I didn't have any cousins my own age. All sorts of things.*" (P12). Yet, the prolonged diagnostic process was felt to impact the timely provision of support. Indeed, several participants reported that, by the time they received their diagnosis, their support options were limited, or, in some cases, non-existent.

Subtheme 2: Difficulties in Finding the Right Support

Support was often perceived as inadequate, and our participants reported facing significant barriers to access. A recurring challenge described in this regard was the disparity in support availability between urban and rural areas, with participants from rural locations reporting a dearth of services within their communities: "*[Where I live is] like the back end of nowhere, the services are pitiful*" (P03). Financial constraints exacerbated these issues, as participants often struggled to cover the costs associated with travel and participation in support programs: "*I haven't really found [any support] too close to me. I found somewhere but it would take two and a half hours to access them, and it takes time and money, and it's stuff, resources, that I don't have*" (P10). Similarly, participants explained that constrained finances impacted their ability to fight for support: "*Fighting [for support] costs a lot of energy and money, and there are times where you just have to let things go because you don't have [those]*" (P12). More broadly, participants also suggested that autistic people with multiple marginalized identities may face greater challenges in terms of self-acceptance and access to support:

> *Being from a South Asian background has impacted the support I have access to as having a disability is incredibly looked down upon in the South Asian community, which made me quite afraid to reach out for support in case someone finds out and then I'm shunned for it.* (P11)

Support groups were consistently highlighted in this regard, as they were perceived to help attendees make friends, develop practical coping strategies and foster a sense of belonging: "*[Support groups make] you feel more empowered because you share* *experiences and you realize there are other people who are going through the same stuff as you and you talk about how to manage it. You feel heard*" (P01). Yet, participants highlighted the challenge of attending support groups where they felt like they had little in common with others. For example, some participants noted that they had never seen another autistic person who looked like them ("*I've never actually met someone else who looks like me, who's autistic*"; P02) while others had never met another autistic person from a similar background to them: "*it's not as common in my area [to go to university] … I've never met another autistic person like me that has gone to uni[versity]*" (P09). This lack of representation was felt by some participants to be an isolating experience: "*it can feel really isolating, interacting with other people, but then always feeling a bit different from them*" (P02). Nonetheless, some had identities that they perceived as being well-represented, relative to others: "*I see representation like being autistic and like LGBTQ+ … but I don't see representation for my skin color very much*" (P02).

Some participants also encountered difficulties in finding support groups that catered to their multiple conditions or identities. Autism-specific groups, for instance, were sometimes perceived to lack an understanding of other co-occurring diagnoses, while other groups failed to comprehend the particular challenges autistic people may face: "*I've tried mental health support on the NHS, but that is from people who haven't worked with people who have autism, and I often feel like I'm misunderstood, and it makes me feel more alone*" (P10). Some participants felt there was a complete lack of services that acknowledged, and catered to, their multiple marginalized identities: "*I find it incredibly difficult to find support for over 18s which is girls only. I am Muslim so I would prefer if it was women's only … [and it] would make Muslim parents more willing to support their children*" (P11). As such, several participants discussed the possibility of targeted groups for those with multiple marginalized identities: "*It may help people to feel more seen if the content [is] tailored to their experiences. I have never seen any advice [for] an autistic person in a wheelchair … it would mean a lot to feel included*" (P13).

Nonetheless, our participants highlighted that not all autistic people will require the same type or level of support, even if from the same background. For example, while many sought social support, some did not feel ready for social groups ("*I think I would be a little too uncomfortable with [groups] because I don't do well in group settings*"; P08), and others sought more practical assistance: "*I am most inclined to accept support regarding academia or skill building … [support] that would help me to work through some of the problems I am currently facing which may be related to my autism*" (P05). Similarly, participants varied in their preferences for support delivery, with some favoring online platforms and others preferring in-person interactions. Despite such variability in support preferences, clear structures, information in advance, and multiple methods of communication were considered useful elements that improved support experiences for all:

> *If [the adverts are] not easily accessible to screen readers and all different types of people, then they're not going to get all types of people interested never mind kind of [attending]. And if they're advertising it, then they need to advertise the access arrangements that are automatically available and also say that there will be more if needed.* (P12)

Beyond such adjustments, participants highlighted the importance of well-matched support. Indeed, one participant highlighted, "*The right support is life-changing and the wrong support is life-ending*" (P12).

Subtheme 3: Unequal Access to a Key Champion

When participants were placed in supportive educational environments and/or had parents who advocated on their behalf, experiences were described as positive. Yet, not all individuals had equal access to such structures. For example, one participant explained that staff at their faith school lacked knowledge about autism ("*I went to a Muslim faith all-girls school … not many people in my secondary school were educated about autism, as in South Asian cultures … hav[ing] a disability like autism is very looked* *down upon"*; P11), which was felt to negatively impact their experiences: "*I was called 'dramatic' and 'overreacting' when I would have a meltdown … to them, I was faking being overwhelmed by noise to avoid going to lesson*" (P11). Further, not all participants had parents/carers who were capable of, or willing to, advocate for them. For example, one participant explained that, as a result of their father's own poor experiences with services, related to his cultural background, he did not encourage them to access support services: "*My dad would never encourage me to [access support] … he's always been suspicious of social services and stuff [because] they misunderstood his background and stuff*" (P02). Similarly, for some parents, English was a second language, making advocating for support on behalf of their child(ren) harder: "*As my parents are not the most fluent in English, they let me find my own support*" (P11). Consequently, many participants found themselves in the position of having to advocate for themselves.

Discussion

Taking a participatory research approach, our team of autistic and non-autistic researchers examined the support experiences of 13 autistic young people with multiple marginalized identities. Despite our interview schedule including specific questions about experiences related to having multiple marginalized identities, participants spent much time discussing the more general barriers that autistic people face when accessing support. This observation may be because of the inherent complexity involved in isolating and articulating these intersectional experiences, or because participants found it challenging to gauge how their experiences might differ from those of other autistic people with different backgrounds or privileges. In any case, our participants appeared to have qualitatively similar experiences to those of the general autistic population: the journey to a diagnosis was long and fraught,[14,44] support was lacking,[45] and many had to fight – with help from their parents – to access the support that did exist.[43] Nonetheless, while these experiences align with those of the broader autistic community, our findings suggest that for autistic people with multiple marginalized identities, these challenges are amplified and compounded, creating additional layers of complexity in accessing and navigating support systems. In the following section, we contextualize our findings with reference to existing research, and offer recommendations for future universal and targeted support programs.

While accessing support is evidently a challenge for many autistic young people, our findings demonstrate how these widespread challenges are compounded for autistic people with multiple marginalized identities, leaving them at a disadvantage relative to their peers. For example, our participants reported facing particularly challenging delays in receiving their autism diagnosis, which were perceived to be, at least in part, attributable to misconceptions and stigmatization around their multiple marginalized identities.[20–24] Such delays had negative impacts on the support available. Indeed, all our participants with a formal diagnosis only received their diagnosis during their teenage years, by which point, they noted a considerable lack of support. This was especially the case as support was perceived to be predominantly targeted at young children.[46]

Where support did exist, our participants reported several barriers to access. For example, participants residing in rural locations reported a scarcity of services within their communities, and financial constraints made participation in support programs challenging. Beyond barriers to access, existing support was perceived as inadequate, with participants highlighting a dearth of services that catered to their multiple marginalized identities. Participants also noted a lack of representation within existing support structures, which left them feeling isolated and alone. Finally, our participants highlighted that autistic people with multiple marginalized identities may not have equal access to a key ‘champion’ to advocate for their needs, leaving them at a relative disadvantage.

In light of the compounded challenges that autistic young people with marginalized identities face, our study aimed to determine whether autism services and supports could be made more accessible and inclusive, or whether more targeted supports were needed. Our findings demonstrate that there is no one-size-fits-all response. Indeed, we found no clear consensus among participants or within our research team, with our results and team discussions ultimately suggesting that a combination of both approaches may be necessary. Regarding targeted approaches, participants suggested the possibility of targeted support for specific sub-groups of the autistic population (e.g., for women/girls, or for people from particular cultural or religious backgrounds). This recommendation aligns with previous research findings, which suggest that some groups may benefit from tailored support that acknowledges the interplay of their multiple identities. .[32,33,47,48] The development of tailored programs warrants further research regarding the particular needs and experiences of sub-groups within the autistic community. Such research should be conducted in collaboration with people with lived experiences within these communities, to ensure it is sensitive to the particular needs of the groups they seek to benefit.[49,50]

While tailored support options were favored by several of our participants, careful consideration must be made to avoid the inadvertent further marginalization of minority groups through the implementation of tailored support initiatives. Indeed, previous studies have demonstrated the value of diversity within support programs, with attendees appreciating the opportunity to meet autistic people at different 'stages' of their journey and from different backgrounds.[51,52] We must also highlight that our participants suggested autistic people are likely to have different support needs and preferences, even if they come from similar backgrounds. For example, participants had varied preferences related to support delivery, as well as the type of support they required. Indeed, while some participants wanted better access to group-based support, others indicated they would not access support in a group setting, either because group interactions were anxiety-provoking, they were concerned about being the 'odd one out', or they preferred more practical, skill-based support. Existing evidence also suggests that people who have not yet come to terms with their autistic identity, or are not openly autistic, may not feel comfortable sharing their experiences with others.[54] This may be especially the case for autistic people with multiple marginalized identities, as our participants suggested they may face particular challenges in developing a positive autistic identity.

As such, tailored support options could be considered an adjunct – and not a replacement – for inclusive, more universal support options. In this regard, our participants suggested the use of clear structures, information in advance, and multiple methods of communication to ensure broader groups are accessible to all (see also Nicolaidis et al.[53]). The tiered model of support adopted by the UK's National Health Service may provide another potential structural solution in this regard. Under this model, universal, preventative services are provided at tier 1, targeted specialist community services like support groups at tier 2, more individualized, tailored support at tier 3, and in-patient care and support at tier 4, with support being stepped up or down tiers as needed over time.[55] However, concerns were raised by the autistic researchers within our team that rigid tiering could lead to further marginalization if individuals are pre-emptively deemed 'too complex' for a given tier. Input from autistic people themselves will therefore be essential to ensure any tiered model flexibly aligns support with individuals' self-determined needs and preferences.

Beyond challenges with extant services, our participants highlighted inequity in access to parental advocacy, which was seen as important, if not essential, for access to timely and appropriate support. [43] For example, our participants highlighted that not all parents possess the tools or language to advocate for their children, while others may face cultural stigma which discourages access to support. As a result, many of our participants were left needing to advocate for themselves. To ensure equality in access to support, it will be essential to move away from a system that relies heavily on parents fighting for support for their children, toward a more proactive system that provides support without advocacy prerequisites. Such systemic disparities may be further dismantled by providing bespoke support for those who may not have access to significant parental advocacy (e.g., autistic people whose parents have English as a second language, autistic people in care). Ultimately, such transformations in support would ensure that all autistic people have equal access to the supports they need to thrive, regardless of their background or identities.

Our findings also point toward a need for practitioners to adopt principles of cultural reciprocity and cultural humility in autism support services. Cultural reciprocity involves a mutual and respectful exchange of knowledge between service providers and people from diverse cultural backgrounds.[56] This approach could help address the concerns raised by our participants about the lack of representation and understanding of their multiple marginalized identities within existing support structures. Complementing this approach, the practice of cultural humility[57] encourages professionals to engage in ongoing self-reflection, recognize the limits of their cultural knowledge, and to engage autistic people and their families with openness and respect. This approach may be particularly relevant given our participants' experiences of feeling isolated or misunderstood due to their intersecting identities. By embracing cultural humility, support providers can create more inclusive environments that acknowledge and validate the diverse experiences of autistic people with multiple marginalized identities. Moreover, this approach can help address the power imbalances that often exist in support settings, fostering a more equitable and collaborative relationship between service providers and autistic people.

Emerging initiatives have been designed to improve support experiences for the broader autistic community. For example, Beresford and colleagues[58] evaluated the use of ‘Specialist Autism Teams’ (community-based, multidisciplinary services for autistic people) that were implemented to address gaps in support. Their evaluation yielded promising results: users who received diagnosis and support from the teams showed improved quality of life and mental health outcomes after one year compared to those just receiving diagnosis, and qualitative feedback highlighted the particular benefits of extended psychoeducation and post-diagnosis support. Such initiatives are not yet widespread, however, and our findings suggest they may not fully address the needs of autistic people with multiple marginalized identities. As such, there is an urgent need to not only improve general access to support, but also to ensure these supports are able to meet the needs of those with multiple marginalized identities. Future research and policy development is warranted in this regard.

Strengths and Limitations

This study was commissioned and designed to inform the development of a specific support program, *Understanding You, Discovering You.*[36,37] Despite the focused aim of the research, the insights generated have much wider applicability, extending beyond the scope of a single support program. A significant strength of the current study is its participatory research design. Involving autistic co-researchers with multiple marginalized identities in the design, data collection, and analysis phases allowed for a more authentic and nuanced understanding of the experiences of this group, as well as more sensitive consideration of the implications of our work. As such, this collaborative approach ensured that the research was more attuned to the actual needs and perspectives of autistic people with multiple marginalized identities.

Nonetheless, three key limitations should be acknowledged. First, we recruited all participants by sending online adverts to the networks of three UK-based autism charities. As such, we may have inadvertently excluded people who do not engage with, or have access to, online support networks, or those who do not actively seek online support. Second, to prevent the demographic questionnaire from becoming burdensome, we collected information regarding a limited number of demographic characteristics (i.e., gender, age, location, and marginalized characteristics reported). As such, we lack comprehensive data on our participants' demographic backgrounds (e.g., their race/ethnicity). Finally, while our study focused on the experiences of autistic people with multiple marginalized identities, we were unable to comprehensively explore all possible intersectionalities. For example, we were unable to recruit any participants from a care background and we did not reach any autistic people with intellectual disabilities. Future research should strive to delve deeper into different intersections to provide a more nuanced understanding of the complex challenges faced by a broader range of autistic people.

Conclusion

Through our co-produced research, we captured the views and experiences of a group of autistic young people who have traditionally been underserved and overlooked in research: those with multiple marginalized identities. We found that, while accessing support is challenging for all autistic people, it may be especially challenging for this group. We suggest that a personalized, compassionate approach to support, which recognizes each individual's intersecting needs and preferences, is warranted. A combination of targeted support options, more inclusive services, and a move away from the reliance on parental advocacy, may ensure more equitable support access for all autistic young people. Future work must continue to platform diverse voices to guide necessary reforms in support provision and ensure support structures cater to the needs and wants of all autistic young people.

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CRediT Authorship Statement

Jade Davies: Conceptualization, Methodology, Formal analysis, Writing – Original draft, Writing – Review & editing
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Will Mandy – Conceptualization, Writing – Review & editing
Kate Cooper – Conceptualization, Writing – Review & editing, Supervision
Laura Crane – Conceptualization, Methodology, Writing – Review & editing, Supervision, Funding acquisition

Author Disclosure Statement

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Supplementary Material

Supplementary Materials A. Interview Guide.

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Table 1.

Demographic Characteristics of Participants (n = 13)

Variable	*n*	%
Gender		
Female	8	61.5
Male	2	15.4
Other	3	23.1
Age M (SD)	20.4	(2.75)
Geographical location		
South East of England	4	30.8
South West of England	2	15.4
London	2	15.4
North West of England	1	7.7
West Midlands	1	7.7
Yorkshire & the Humber	1	7.7
Scotland	1	7.7
Wales	1	7.7
Marginalized characteristics reported[a]		
Live in a low-income household	11	84.6
LGBTQ+	8	61.5
From a non-White ethnic group	6	46.2
Have a co-occurring disability	6	46.2
Come from a single-parent family	4	30.7
Minority gender	3	23.1
Live in a rural area	3	23.1
Have a minority faith/religion	2	15.4

I come from an immigrant family	1	7.7
Other[b]	3	23.1

[a] Percentages do not add up to 100% as categories are not mutually exclusive.

[b] Participants were able to report additional underrepresented characteristics, over and above the categories already identified. Three participants reported additional underrepresented characteristics, including drug-induced psychosis and being a young carer.

Table 2.

Process of Reflexive Thematic Analysis.

Stages of analysis	**Details of the process**
1. Familiarization with the dataset	JD, LI, and SC familiarized themselves with the data by conducting the interviews and/or reading and re-reading the interview transcripts.
2. Generating initial codes	JD, LI, and SC used Microsoft Word to generate and add semantic (surface-level) and latent (subjectively interpreted) codes to the transcripts.
3. Searching for themes	JD, LI, and SC grouped overlapping or duplicate codes to generate preliminary ‘themes’ that summarized salient aspects of the data.
4. Reviewing themes	JD, LI, and SC presented the preliminary themes to BR and LC. As a group, we refined the themes and structure of the findings.
5. Defining and naming themes	When the theme structure was finalized, JD drafted the initial findings, and sent a draft to all authors. Minor adjustments were made at this stage to ensure the theme names adequately described the content and essence of the theme.
6. Producing the report	All authors reviewed and agreed upon the findings. LI and SC chose a series of quotations to be included in the final report.