

**Table I**

## Inclusion &amp; Exclusion Criteria

Inclusion	Exclusion
<ul style="list-style-type: none"> <li>Qualitative or mixed-method studies where qualitative data are reported separately.</li> <li>Participants identify as autistic (formal diagnosis or self-identifying) and have been diagnosed/identified in adulthood (18+)</li> <li>UK Based</li> <li>Studies in English Language</li> <li>Studies relate to the experiences of mental health support for late-diagnosed autistic adults. More generalised studies will only be included if they include specific information on the experiences of seeking and/or engaging with mental health support</li> </ul>	<ul style="list-style-type: none"> <li>Studies where participants are family members/carers who are reporting on the experiences of autistic people, unless family members/carers are assisting the participants rather than reporting their experiences.</li> <li>Studies where age of diagnosis was not sought or where data from late-diagnosed participants cannot be identified.</li> <li>Studies involving animals</li> <li>Studies outside of the UK</li> </ul>

**Table II***Study Characteristics*

Study ID	Author	Year of Publication	Study		
			Location	Setting, if applicable	Study Design
1	Griffith, Totsika, Nash & Hastings	2012	Wales &		IPA
			England		Interviews
2	Leedham, Thompson, Smith Freeth	2019	England		IPA

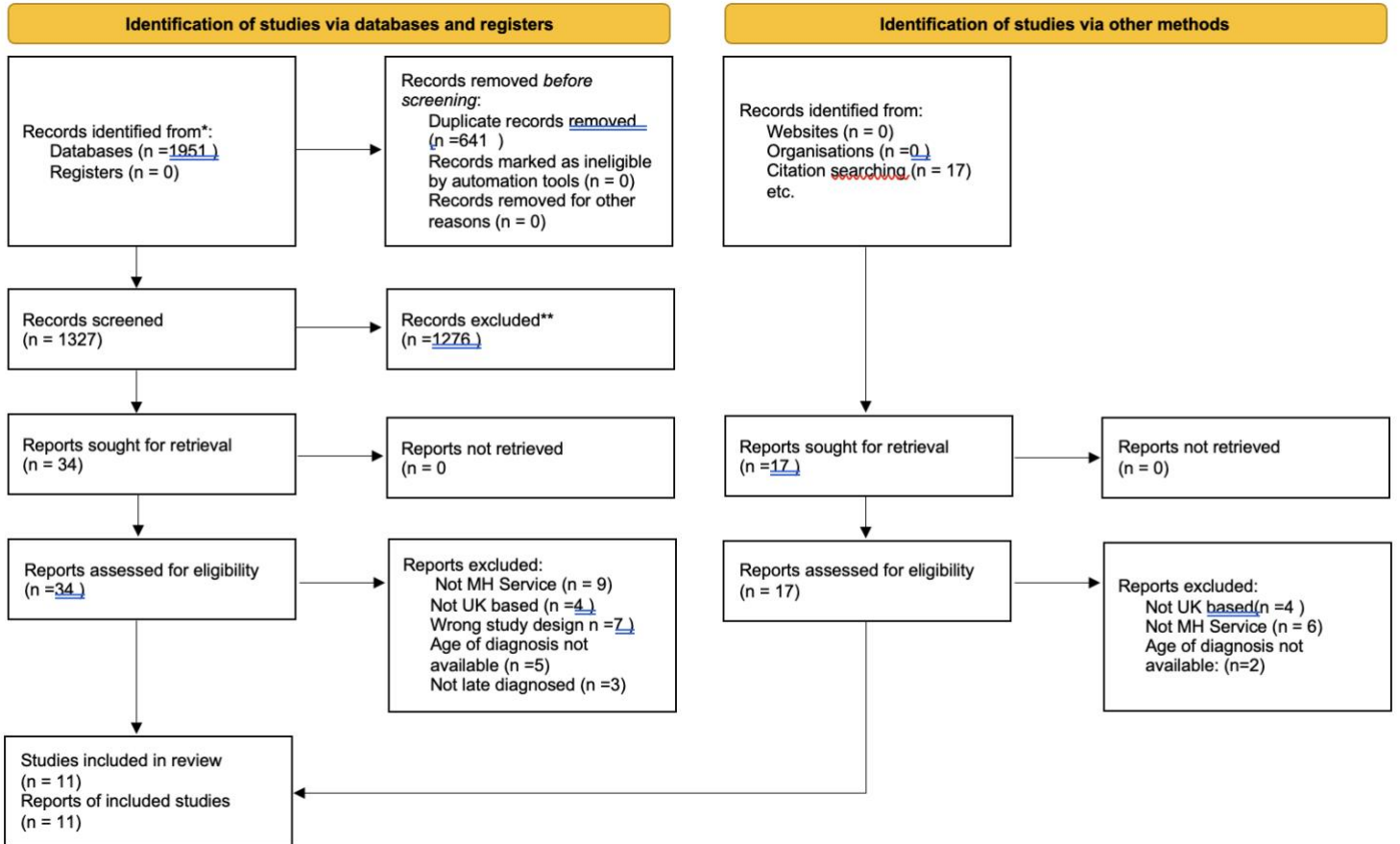
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4		Finch, Mackintosh,				
5		Petrou, McConachie, Coutea,				TA
6		Garland & Parr	2022	England		interviews
7	3					TA of Blog
8						based
9						
10				United	Online	
11				Kingdom	blogs	study
12	4	Harmens, Sedgewick & Hobson	2022			
13					Post	
14					Diagnostic	TA
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16	5	Hatton & Lee	2022	England	Service	interviews
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20						
21					Perinatal	TA
22	6	Pentz, Cooke & Sharp	2023	England	MH	interviews
23						TA of
24						Online
25		Au-Yeung, Bradley, Robertson, Shaw,		United		
26	7	Baron-Cohen and Cassidy	2019	Kingdom		Survey
27						
28					NHS Adult	
29					Autism	
30					Services in	
31						
32		Russell, Gaunt, Cooper, Horwood,			Bristol &	TA
33	8	Barton, Ensum, et al.	2019	England	Newcastle	interviews
34						
35						
36	9	Bargiela, Steward & Mandy	2016	Kingdom		FA
37						Interviews
38						
39	10	Stagg & Belcher	2019	Kingdom		TA
40						interviews
41						
42					NHS Eating	
43					Disorder	
44						
45	11	Babb, Brede, Jones, Elliot et al.	2021	Kingdom	Inpatient	TA
46					Unit	interviews
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**Table III**  
**Participant Characteristics**

Study ID	Sample Size	Age Range & Mean	Age of Diagnosis Range & (Mean)	Gender
1	11	37-57 (46.6)	19-50 (37.8)	7 Males, 4 Females
2	11	43-64 (50.8)	40-62 (47)	11 Female
3	29	20-71 (43)	6-67 (43)	16males,13females
4	6		20-49	6 females
5	14	19-61 (31)	none given but 18+	6 male, 8 female
6	5	24-33	24+	5 females
7	71	20-57(40)	20+	60 females, 11 males
8	21	21-60	19 Participants were 20+	17 Male, 4 Female
9	14	19-30	12 participants diagnosed 19-30,	14 female
10	9	52-54	42-54	5 female, 4 male
11	15	23-58	(29.4)	15 female

**Figure I**

*PRISMA Results*



PRISMA

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## Mental Health Support Experiences of Late Diagnosed Autistic Adults

**A Systematic Review of the Mental Health Support Experiences of Late Diagnosed Autistic Adults in the UK****Abstract**

**Originality/Value:** While research with autistic people diagnosed in adulthood is growing, they remain an understudied population; few studies have investigated mental health support experiences of late diagnosed autistic adults. Rates of receiving an autism diagnosis in adulthood are increasing, particularly among women and gender-diverse populations. **Purpose:** This systematic review summarized qualitative evidence on the experiences of late diagnosed autistic adults engaging with mental health support in the UK. **Methods:** Data from 11 studies were analysed using accounts from 206 participants. **Findings:** Superordinate themes were: *It Felt Like They Didn't Care* (subthemes: *Dismissed & Misunderstood, Harmful, Not Helpful*;) *Light at the End of the Tunnel* (subthemes: *Finding What Fits, Listening to Autistic Voices*). Participants described frustrating experiences in accessing mental health support both prior to and post diagnosis. Facilitators to positive mental healthcare included autism informed professionals and services that understood autistic people's needs. Post-diagnostic supports emphasizing a sense of community and self-acceptance were identified as helpful for good mental health outcomes. This review supports the importance of ease of access to autism assessment, appropriate service-wide trainings for mental health professionals and gatekeepers, and the urgent need for timely neuroaffirmative post-diagnostic support for adults receiving a late diagnosis.

**Keywords:** Autism, Autistic Adults, Mental Health Support, Late Diagnosed Autism, Service Experience

## Mental Health Support Experiences of Late Diagnosed Autistic Adults

### 1. Background

Recent progress in both public and clinical understanding of autism, including the broadening of diagnostic criteria, has led to an increased rate of late diagnosis/identification of autism in adults. Throughout this study, we will use the term late diagnosed, for the purposes of this research, late diagnosed will refer to adults who have received an autism diagnosis at aged 18+. These adults—sometimes described as the “lost generation”—have navigated childhood, adolescence, and often significant portions of adulthood without recognition of their autism (Ghanouni & Seaker, 2023; Lai & Baron-Cohen, 2015). Age of diagnosis has been identified as a key factor influencing outcomes for autistic individuals, with later diagnosis associated with poorer mental health and lower quality of life (Atherton et al., 2022; Huang et al., 2020). While this growing recognition reflects advances in awareness, it also highlights a systemic delay in identification that may shape long-term outcomes. Evidence points to gender-related biases in diagnosis, indicating that women and gender-diverse individuals are more likely to be overlooked or receive a diagnosis later. This is often linked to camouflaging behaviours and diagnostic criteria that have historically been based on male presentations (Hull et al., 2017; Loomes et al., 2017). Moreover, systemic issues within healthcare—such as insufficient clinician training and a shortage of autism-informed services—play a significant role in limiting access to appropriate care. (Mason et al., 2019)

Rates of co-occurring mental health diagnosis are high in autistic adults. Anxiety disorders have been reported at 20% in autistic population compared to 7.3% in the non-autistic population (Maitland et al., 2021). Additionally, a common experience of late diagnosed autistic adults is having received misdiagnoses of psychiatric conditions prior to being identified as

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4 autistic. In particular, late diagnosed autistic women report that they have been misdiagnosed  
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6 with personality disorders prior to their autism being recognised, while late diagnosed autistic  
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8 males report that they have been misdiagnosed with both depression and anxiety disorders prior  
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10 to their autism diagnosis (Kentrou et al., 2024). Receiving misdiagnoses of psychiatric  
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12 conditions can have harmful psychological consequences for autistic adults, who report feelings  
13  
14 of confusion and frustration and ineffective medication and therapies. Some of these adults have  
15  
16 described a complex re-adjustment of recognising their difficulties were stemming from  
17  
18 undiagnosed autism, rather than the psychiatric conditions they felt they had been misdiagnosed  
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20 with (Dell’Osso & Carpita, 2023; Gesi et al., 2021; Kentrou et al., 2024; Lupindo et al., 2022).  
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22 Although these patterns are well-documented, there is limited critical discussion of how  
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24 diagnostic overshadowing and gendered biases within clinical practice contribute to these trends.  
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29         When seeking support for mental health difficulties, autistic adults have reported that  
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31 mental health service provision is often insufficient and unhelpful, describing higher levels of  
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33 unmet needs in mental health support compared to non-autistic adults (Nicolaidis et al., 2013).  
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36         However, much of this evidence is drawn from mixed or predominantly non-UK samples,  
37  
38 potentially limiting its applicability. Furthermore, existing studies often focus broadly on autistic  
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40 adults, without distinguishing the potentially unique experiences of those diagnosed later in life,  
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42 whose interactions with services may be shaped by prolonged periods of misidentification and  
43  
44 possible inappropriate care. Consequently, there remains a lack of synthesis specifically  
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46 examining how late-diagnosed autistic adults experience mental health services, particularly  
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48 within the UK healthcare system. This represents a significant gap, as healthcare structures,  
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50 policies, and service delivery models vary internationally and may influence both access to and  
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52 quality of care. Focusing on UK-based services allows for a more coherent analysis of systemic  
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54 factors and their impact on this population. We will focus on qualitative data to better hear the  
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## Mental Health Support Experiences of Late Diagnosed Autistic Adults

voices of late diagnosed autistic adults about their own experiences. It is imperative that we amplify the voices of members of this community in order to design better supports for them.

### 2. Methods

This review, registered on the PROSPERO database (Registration No. CRD42023483034), adhered to the Preferred Reporting for Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. (Page et al., 2021)

#### 2.1 Positionality

The neurodiversity paradigm reconceptualizes autism as a difference in cognitive and emotional processing, rather than the deficit-based medical model of autism. Many autistic people and autism advocates support the neurodiversity paradigm and the changing face of autism research, in a move toward positively impactful and participatory approaches in line with the needs of the community (Botha & Gillespie-Lynch, 2022). In undertaking this review, the research team adopted this positionality.

#### 2.2 Searches

Four electronic databases were searched to identify relevant published studies that meet the inclusion criteria of this review: PsycINFO, Medline, Web of Science, and CINAHL. There were no restrictions on dates of publication. All reference lists from included articles were also screened for relevant additional works and citation search was carried out using Web of Science. Furthermore, to identify additional references, existing similar systematic reviews and meta-

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analyses were reviewed. Grey Literature was searched for relevant data including ProQuest Dissertations. References were managed using Endnote and Rayyan. Searches were first run in January 2024 and rerun in May 2024 prior to analysis to include any additional studies published since the initial search. There was no limit on dates. Please see supplementary materials for an example search.

### **2.3 Eligibility Criteria**

This review focused on empirical peer-reviewed qualitative studies, and mixed-method studies where qualitative data were reported separately. Studies were included if they explored the mental health support experience of late diagnosed autistic adults. Broader studies of the experiences of late diagnosis were included where participants spoke specifically about their mental health support experiences. Participants were required to be autistic adults aged 18 or over who had been diagnosed in adulthood (aged 18+). As this review sought to understand the experience of late diagnosed adults who were living in the UK, only UK based studies were included. Table 1 lists inclusion and exclusion criteria.

#### **Table I**

##### ***Inclusion & Exclusion Criteria***

### **2.4 Data Extraction and Quality Assessment**

Eligible full texts were subjected to data extraction and quality assessment by the primary author. Data were extracted using Rayyan and Endnote 20. The Critical Appraisal Skills Toolkit (CASP) Checklist for Qualitative Studies (CASP, 2018) was used to assess quality of the studies included in this systematic review. CASP is a tool for assessing methodology, evaluating

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credibility, considering ethics and reflecting on limitations on qualitative research. The results section of each article was extracted for analysis.

### 2.5 Data Synthesis

Data synthesis was conducted following guidelines for thematic synthesis (Thomas & Harden, 2008). In thematic synthesis, findings from multiple qualitative studies are synthesized based on the principles of thematic analysis. Thematic synthesis is used for systematic reviews in order to be able to generate new concepts and understanding from bringing together the primary studies. Data extracted from the studies were exported to NVivo Version 14 Software (Lumivero, 2023) to support the data synthesis process. The analysis was inductive in that the researcher created the codes and themes from the data. Coding was first done line by line and developed in a cyclical rather than linear way, meaning the researcher returned numerous times to redefine codes and to begin to group similar and reoccurring codes into code categories. Consistency in coding and theme development was ensured through an iterative process involving repeated review of the data, ongoing refinement of the coding framework, and regular comparison of codes and themes across studies.

## 3. Results

### 3.1 Study Selection

Throughout the process of identifying the included studies, the researchers followed the guidelines stated in the PRISMA Statement of Preferred Reporting Items for Systematic Reviews and Meta-analyses (Moher et al., 2009). Combined database searches identified 1951 papers and reference list searches identified 17 additional papers. After removing duplicates, 1327 papers

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4 were screened by title and abstract, resulting in 51 articles for full text screening. Full text  
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6 screening was conducted for 51 articles, 40 studies were excluded, and 11 studies were  
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8 included. Second screening was carried out by AH. Disagreements on inclusion were resolved  
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10 through discussion until consensus was reached. Details of exclusions can be found below in  
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12 Figure 1.  
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### Figure I

#### *Prisma Results*

### 3.2 Study Characteristics

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29 Ten studies were qualitative and one mixed-methods, of which only the qualitative data  
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31 was included. All participants were included from ten studies as age of diagnosis data were  
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33 available. For one study, (Harmens et al., 2023), 6 out of 23 participants were included and only  
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35 their relevant data were included in the analysis; the 6 participants included were late diagnosed  
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37 and the 17 participants excluded were diagnosed in childhood . A total of 206 participants were  
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39 included across all eleven studies. There were 145 female participants and 61 male participants.  
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42 The age range of participants was 19-71 years.  
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### Table II

#### *Study Characteristics*

### Table III

#### *Participant Characteristics*

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### 3.3 Quality Assessment Results

All studies included in this systematic review were assessed for quality using the Critical Appraisal Skills Toolkit (CASP) Checklist for Qualitative Studies (CASP, 2018).

Based on the CASP checklist for each study, ten studies were deemed to be high quality and one study was deemed to be moderate quality. All eleven studies were therefore included in the analysis. The first author (LC) reviewed all 11 studies, while 30% of studies were also reviewed by author CH. Any discrepancies were discussed and resolved through consensus between the two reviewers.

### 3.4 Thematic Synthesis

The following two main themes, each containing two subthemes, were constructed from the data:

Theme 1 – It Felt Like They Didn't Care

Sub Themes: 1. Dismissed & Misunderstood

2. Harmful, Not Helpful

Theme 2 – Light at the End of the Tunnel

Sub Themes: 1. Finding What Fits

2. Listening to Autistic Voices

***Theme 1 – It Felt Like They Didn't Care***

***Sub Theme: 1. Dismissed & Misunderstood***

## Mental Health Support Experiences of Late Diagnosed Autistic Adults

Late diagnosed autistic adults faced barriers and accessibility issues both before diagnosis and after receiving a diagnosis as an adult. The reported challenges echo similar experiences of autistic adults in general, however, the unique experiences of late diagnosed adults who have gone through mental services undiagnosed and/or accessed mental health services after diagnosis in adulthood are illuminated here. Experiences of being dismissed and misunderstood by professionals were widespread across several studies. Autistic adults described the barriers to accessing mental health services both before receiving a diagnosis and while awaiting assessment, including being refused referral to services and not being taken seriously by mental health professionals. These experiences of dismissal can be understood not only at an individual level, but as reflecting broader systemic limitations within mental health services. In particular, they suggest a lack of integration of autism-informed perspectives within mental healthcare.

In particular, anxiety concerning attending the GP was a common experience. Many autistic adults found that attempting to access mental health support via GP was “*stressful and unsuccessful*”<sup>1</sup>. Commonly, there was a fear of being dismissed and not being taken seriously by GPs when attempting to access autism diagnostic services: “*My years of masking, coupled with an apparent high level of ‘functioning’, and an inability to ask for help, meant that persuading my GP to refer me was too anxiety provoking, I had heard stories of women being refused referral due to eye contact with the GP*”<sup>4</sup>. Throughout the data, the experiences of dismissal while considering and awaiting autism assessment were widespread: “*When I mentioned the possibility to my psychiatric nurse she actually laughed at me...*”<sup>9</sup>. When people are denied autism assessments, they may go undiagnosed, further exacerbating mental health issues and complicating access to appropriate and helpful mental health support. Autistic adults described feeling that when they disclosed to professionals that they were awaiting assessment for autism it “*was not taken seriously by clinicians*”<sup>6</sup>. The anticipation of being dismissed appears to shape

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support-seeking behaviour, with some individuals delaying or avoiding engagement with services altogether. This highlights a potential cyclical relationship, whereby prior negative experiences can reinforce barriers to services, potentially furthering unmet mental health needs.

Autistic adults expressed their hope that “*receiving a formal diagnosis might remove that barrier*”<sup>6</sup> to accessing the mental health support they need. However, this was often not the case, even after having received a diagnosis, many autistic individuals still experienced being dismissed by mental health services and felt that professionals did not understand them; “*It felt exhausting to explain over and over again what me being autistic really meant, how it affected me*”<sup>4</sup>. These findings indicate that receiving a diagnosis alone is insufficient to improve experiences without corresponding changes in professional’s awareness and service provision. This points to a disconnect between diagnostic processes and therapeutic practice, where autism is recognised in principle but not meaningfully integrated into care.

Mental health professionals’ lack of ability to understand autistic traits and differentiate them from mental health symptoms was a cause of frustration for many, particularly related to sensory coping mechanisms: “*When I was in hospital, I kept getting told off for walking on tip toes and for fidgeting a lot . . . they thought I was doing these things to burn more calories, except I’d been doing them for as long as I could remember*”<sup>11</sup>. Autistic features and the needs of autistic people within mental health services did not appear to be adequately understood or considered across varying settings, even after diagnosis, including inpatient eating disorder wards and Dialectical Behavioural Therapy (DBT) skills groups: “*It felt like they didn’t care . . . I used to like to sit in the same seat, just because I knew where it was, and every day a different staff member would go and sit there. And they wouldn’t understand why I was getting upset.*”<sup>11</sup>. It was common among autistic adults to feel that they were often dismissed due to not “*fitting in to labelled categories*”<sup>2</sup> and “*falling through the gap*”<sup>1</sup>. One individual expressed that her late

## Mental Health Support Experiences of Late Diagnosed Autistic Adults

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4 diagnosis was a barrier to accessing mental health support, as she was dismissed by professionals  
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6 due to her having "*coped this long without support*"<sup>1</sup>; illustrating that ideas of high-functioning  
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8 vs low-functioning held among mental health professionals appeared to negatively affect  
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10 participants experiences with services.

### ***Sub Theme: 2. Harmful, Not Helpful***

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15 Many autistic individuals experienced support from mental health professionals as  
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17 inadequate and felt that professionals who did not have any knowledge or expertise in working  
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19 with autistic people could "*do more harm than good*"<sup>1</sup>. This feeling was echoed multiple times  
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21 within the data, with autistic adults feeling that their experiences of accessing mental health  
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23 support left them "*exhausted and still struggling mentally*"<sup>2</sup>. There were instances when it was  
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25 reported that they received no help or contact from services when they sought mental health  
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27 support; "*I did have a consultant psychiatrist, and the one time when I was really bad, around*  
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29 *Christmas time, I contacted him and he never got back to me*"<sup>10</sup>.

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34 Many late diagnosed autistic adults described negative experiences with Cognitive  
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36 Behavioural Therapy, often feeling it was inaccessible or ineffective for them, with one  
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38 individual describing their experience with Cognitive Behavioural Therapy as "*absolute*  
39  
40 *rubbish*"<sup>1</sup>. People who engaged with CBT and with various group behavioral therapies felt that  
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42 these interventions were inappropriate for their needs and "*often left them with even worse*  
43  
44 *mental health*"<sup>4</sup> and feelings of being "*wrong & defective*"<sup>2</sup>. Communication difficulties with  
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46 cognitive behavioral therapists was a frequent experience, including therapists' perceptions of  
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48 people's readiness for and suitability of elements of CBT – "*maybe the problem is that they*  
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50 *assume you have a lot of these skills already . . . Therefore, I couldn't even begin to make*  
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52 *changes, because I don't have any of those foundational skills*"<sup>11</sup>.

## Mental Health Support Experiences of Late Diagnosed Autistic Adults

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4 A unique experience among late diagnosed adults is the common struggle of trying to  
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6 navigate mental health support while either not knowing they are autistic, or not having yet  
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8 received a diagnosis. Then, even after having accessed assessment and received a diagnosis,  
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10 which is already an emotionally complex experience of “*elating*” and “*frustrating*”, autistic adults  
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12 face a new set of barriers, including lack of post-diagnostic supports and another “*battle to be*  
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14 *recongised by services*”. Compounding this issue was the fact that many individuals had received  
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16 psychiatric misdiagnoses from professionals prior to their autism identification and/or diagnosis,  
17  
18 which led to “*further confusion and self-doubt*”<sup>2</sup>. Autistic individuals, when looking back at their  
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20 pre-diagnosis experiences, expressed frustration with mental health professionals' inability to  
21  
22 pick up on autistic traits and felt that professionals were not able to help them in “*getting to the*  
23  
24 *bottom of what was wrong*”<sup>7</sup>. The length of time spent in services without any professional  
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26 noticing their undiagnosed autism was noted “*Four to five years of depression and anxiety*  
27  
28 *treatment...years of talking therapy...and not once did anyone suggest I had anything other than*  
29  
30 *depression*”<sup>9</sup>. Common experiences of “*masking*”<sup>4</sup> with professionals prior to diagnosis were  
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32 reported by autistic adults.  
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38 Further, it was felt that even after receiving an autism diagnosis, professionals remained  
39  
40 unable to differentiate “*autistic characteristics*”<sup>6</sup> from “*mental health symptoms*”<sup>6</sup>. Professionals  
41  
42 were perceived as having “*not given enough attention*”<sup>6</sup> to the autism diagnosis and not having  
43  
44 the expertise or confidence to adapt therapies. In contrast to the participants in one study who  
45  
46 received structured post-diagnostic support, many people described their difficulties in finding  
47  
48 appropriate services to support them after having been diagnosed autistic, with one participant  
49  
50 quote echoing the feelings of many – “*There’s none, there’s none... you know there’s none*”<sup>11</sup>.  
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### ***Theme 2 – Light At the End of The Tunnel***

#### ***Sub Themes: 1. Finding What Fits***

## Mental Health Support Experiences of Late Diagnosed Autistic Adults

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4 Late diagnosed autistic adults did have some positive experiences with mental health  
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6 services. It is particularly notable that positive experiences were most frequently reported after a  
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8 diagnosis; individuals have described improved mental health after diagnosis and access to post-  
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10 diagnostic support as a “*light at the end of the tunnel*”<sup>5</sup>. Receiving a late diagnosis and having  
11  
12 access to post diagnostic support was described as very helpful and at times “*life changing*”<sup>5</sup> for  
13  
14 people. Positive experiences such as feeling a “*sense of belonging*”<sup>5</sup> and being “*connected to the*  
15  
16 *autistic community*”<sup>5</sup> and “*fitting in*”<sup>2</sup> were reported by adults who had received post diagnostic  
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18 support. People described receiving a diagnosis as “*elating*”<sup>7</sup> and having a positive effect on their  
19  
20 mental health.  
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25 Adults in some services felt that their autism diagnosis led to mental health professionals  
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27 being more understanding around their sensory experiences, for instance, being able to  
28  
29 differentiate their autistic traits from eating disorder behaviours; “*When I explained about*  
30  
31 *needing the food separate, they were very good about accommodating that. And they would*  
32  
33 *separate out the food, and they didn't necessarily challenge that*”<sup>11</sup>. Consideration of sensory  
34  
35 experiences and normalizing of asking questions about sensory needs was described by one  
36  
37 person as being beneficial during her time in a perinatal unit and during the birthing period.  
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41 Despite being seldom reported, positive experiences were had with GP referrals for  
42  
43 autism assessment when GPs were able to recognise the signs of autism in adults. Therapies that  
44  
45 focused on skills building around emotional regulation were reported by many autistic people  
46  
47 as being helpful and useful, particularly elements of Dialectical Behavioural Therapy (DBT),  
48  
49 which is a type of therapy that focuses on managing intense emotions and navigating  
50  
51 relationships. One individual describes a change in coping skills after attending DBT “*Emotion*  
52  
53 *regulation was really important to me . . . when I was in distress, I would just self-harm, just*  
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55 *become very unwell. But after that, I actually started to think what was going on*”<sup>11</sup>.  
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## Mental Health Support Experiences of Late Diagnosed Autistic Adults

The ADEPT Guided self-help program is an NHS specifically designed depression support therapy for autistic adults (Russell et al., 2019). Illuminating the importance of autism informed services, one individual who had attended ADEPT guided self-help program reported that attending autism tailored supports allowed her to “*come out of me shell a little bit more*”<sup>8</sup> and noted that “*It was nice to be able to engage with something and actually feel like it was doing me good*”<sup>8</sup>. Late diagnosed autistic adults experienced mental health support as positive when they felt they were being heard, understood and their needs were being considered.

### **Sub Theme: 2. Listening to Autistic Voices**

As described, perhaps the most important aspect of ensuring mental health services are accessible to late diagnosed autistic adult is asking for, listening to and taking into account the opinions and perspectives of the population. Within the data, many recommendations were given about ensuring the accessibility of services. The importance of considering adaptations, both to the environment and the therapeutic modalities, was highlighted. Autistic adults who had accessed services where they were asked about sensory sensitivities, given specific and clear information about their appointments, and provided with consistency of time and location reported positive and helpful experiences in mental health services. Positive experiences, while less frequently reported, provide important insight into the conditions under which mental health services can be effective. Notably, these accounts suggest that when services adopt flexible, autism-informed approaches, the same systems that previously acted as barriers can become facilitators of support.

Experiences of groups were varied among participants in relation to preference for online or in-person groups, however, smaller groups were generally preferred: “*I tried to do a group and I tried to do DBT which was an online group and I found it too much with too many people. I deal better with smaller groups, and then I do big groups, and I just find it a bit overwhelming*”

## Mental Health Support Experiences of Late Diagnosed Autistic Adults

1  
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4 *having too many people there”<sup>6</sup>. Terminology when describing autistic people was also*  
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6 *suggested as a topic for professionals to consider when working with the population – “People*  
7  
8 *with ASC’ was used a lot which I find quite jarring. It is inherent in me so I prefer Autistic*  
9  
10 *people”<sup>5</sup>.*

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12  
13 An important recurring topic among late diagnosed autistic adults was self-esteem and  
14  
15 self-compassion. The effects of having gone undiagnosed throughout childhood, adolescence and  
16  
17 into adulthood was noted as having an eroding effect on self-esteem. Recommendations were  
18  
19 given for mental health professionals to be particularly mindful of this when working with late  
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21 diagnosed autistic adults and to consider the importance of self-compassion within therapeutic  
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23 interventions.  
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### 4. Discussion

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33 Here we systematically reviewed and synthesised existing qualitative data from 11  
34  
35 studies on late diagnosed autistic adults’ experience of accessing mental health support in the  
36  
37 UK, with the aim to understand the current experiences of this population.  
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40 Findings showed that late-diagnosed autistic adults frequently feel dismissed and  
41  
42 misunderstood by mental health professionals. It was found that the support received from  
43  
44 mental health professionals was not only insufficient, but also potentially harmful, with cognitive  
45  
46 Behavioral Therapy (CBT) and some group therapies deemed inappropriate, ineffective, and  
47  
48 sometimes exacerbating mental health issues. Furthermore, late diagnosed autistic individuals  
49  
50 expressed frustration over being misdiagnosed with various psychiatric conditions before their  
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52 autism was identified and felt that mental health services were often not equipped to address  
53  
54 their needs, even after diagnosis.  
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## Mental Health Support Experiences of Late Diagnosed Autistic Adults

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4 Positive experiences were more likely to occur after participants received an autism  
5 diagnosis and accessed post-diagnostic support. The importance of mental health professionals  
6 actively listening to and considering the perspectives of late-diagnosed autistic adults was  
7 emphasized. Service-wide training on autism, adaptations to therapeutic approaches, and  
8 sensitivity to the unique needs of late diagnosed autistic adults were recommended to improve  
9 accessibility and effectiveness of mental health services.  
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17 The findings of this review align with recent research on the mental health experiences of  
18 autistic adults (Babb et al., 2021), as many of the challenges faced by the general autistic  
19 population when engaging with mental health services are also shared by late-diagnosed  
20 individuals. However, there are important distinct differences specific to the late-diagnosed  
21 group. These include difficulties navigating services without knowing they are autistic,  
22 scepticism and dismissal from professionals while awaiting assessment, and a lack of post-  
23 diagnostic support once they receive a diagnosis. These are areas where further research is  
24 urgently needed.  
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36 Autistic adults diagnosed later in life often have very different life experiences compared  
37 to those diagnosed in childhood (Huang et al., 2020; Lai & Baron-Cohen, 2015). Growing up  
38 without an understanding of their autistic identity, many late-diagnosed individuals report feeling  
39 as though they are “on the outside looking in” or “hiding behind glass” (Lilley et al., 2022),  
40 impacting various aspects of life, including social relationships, education, and the workplace  
41 prolonged experiences of isolation and a lack of belonging can significantly harm self-esteem  
42 and mental well-being (Kelly et al., 2022; Seers & Hogg, 2023). The widespread masking and  
43 camouflaging behaviours noted in the literature on late-diagnosed adults often exacerbate these  
44 mental health challenges (Blainey et al., 2017). Many of these individuals have low support  
45 needs, which can lead to their exclusion from beneficial services (Baldwin & Costley, 2016).  
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## Mental Health Support Experiences of Late Diagnosed Autistic Adults

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4 Perceptions of their 'high functioning' by professionals, a barrier identified in this review, further  
5  
6 hinder access to adequate support. While limited supports exist for autistic children and young  
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8 people in the UK (Galpin et al., 2018; Read & Schofield, 2010), late-diagnosed adults have  
9  
10 missed out entirely on the potential benefits of early professional intervention and peer  
11  
12 relationships during childhood and adolescence. Understanding the long-term impact of this lack  
13  
14 of support is crucial for addressing the unique needs of the late-diagnosed autistic population.  
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16  
17 It is notable that most of the studies included in this review did not intend to study  
18  
19 specifically late diagnosed autistic adults, rather they by chance recruited a sample which  
20  
21 contained all or majority late diagnosed adults. Since the studies did not explicitly aim to explore  
22  
23 issues relevant to late-diagnosed autistic adults, the research design and methods used may not  
24  
25 adequately capture the unique experiences of this group. As a result, the studies may overlook  
26  
27 critical aspects relevant to late diagnosis. Presently, data available on this population are still  
28  
29 limited. While the themes identified in this review offer valuable insights, they are based on a  
30  
31 relatively small number of studies, and the experiences of late-diagnosed autistic adults may not  
32  
33 be fully represented. There is a clear need for more research focused specifically on this  
34  
35 population to better understand their unique mental health challenges and service needs. Future  
36  
37 studies should explore the barriers to accessing support, the effectiveness of different therapeutic  
38  
39 approaches, and the long-term impact of receiving a late autism diagnosis on mental health  
40  
41 outcomes. Until more robust data is available, it is premature to make definitive conclusions  
42  
43 about the best ways to support late-diagnosed autistic adults in mental health settings.  
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50 Most positive experiences with mental health professionals reported by participants were  
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52 often post-diagnosis, due to an increased understanding from professionals and access to a  
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54 community and sense of belonging. NHS England has recently published guidelines "Meeting  
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56 the needs of autistic adults in mental health services" for all integrated care boards to  
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## Mental Health Support Experiences of Late Diagnosed Autistic Adults

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4 implement.. It is stated in the guidance that timely access to post diagnostic support is  
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6 understood to be important for adults receiving a diagnosis, however, the authors note that this  
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8 topic is outside the scope of their review (*NHS England, 2023*). It is clear that further in depth  
9  
10 research is needed into post-diagnostic support for late diagnosed autistic adults and an  
11  
12 exploration of its usefulness in improving mental health outcomes for this population. Currently,  
13  
14 most diagnostic services do not offer post diagnostic support to autistic adults who have received  
15  
16 a late diagnosis (Crane et al., 2018). Post diagnostic support has the potential to improve mental  
17  
18 health outcomes and should be offered to all autistic people diagnosed in adulthood. A recent  
19  
20 and timely systematic review of current UK based post diagnostic supports found that this  
21  
22 population feel post diagnostic support should include access to low-intensity support services,  
23  
24 psychoeducational resources and opportunities for peer connection, with many also showing a  
25  
26 preference for support led by other autistic individuals. (Norris et al., 2025) However, further  
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28 research is needed to understand specifics of how support should be best delivered.  
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### 5. Strengths & Limitations

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40 This review brings together existing research with a particular focus on UK services to provide  
41  
42 an up-to-date overview of the literature. This study highlights the importance of sense of  
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44 community and self-acceptance to the positive mental health of late diagnosed autistic  
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46 adults, promoting a more holistic approach to mental health treatment than may be  
47  
48 currently offered by mental health services in the UK. A limitation of this review is that  
49  
50 many of the studies included did not specifically aim to investigate late-diagnosed autistic  
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52 adults; however, the participants recruited were inadvertently composed entirely or  
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54 predominantly of late diagnosed adults. Although these experiences reflect late diagnosed  
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## Mental Health Support Experiences of Late Diagnosed Autistic Adults

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4 autistic adults' experiences in services, the intention of much of this research was not to  
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6 look at the specific late diagnosed experience. Of the eleven studies included, very few  
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8 studies collected demographic information outside of age and gender. While four studies  
9  
10 collected information about employment and education status and one study included  
11  
12 some information on socioeconomic status (reporting high, medium or low deprivation),  
13  
14 no studies reported any information on ethnicity, sexuality or any other demographic  
15  
16 category. Demographic information is very important to consider intersectional factors in  
17  
18 autism research. Many intersectional factors may contribute to late identification of  
19  
20 autistic adults and their barriers to accessing mental health services. It is a major ethical  
21  
22 concern within autism research to include underrepresented and marginalised groups; as  
23  
24 such, other intersectional identities such as class, gender, race, ethnicity, disability, and  
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26 sexuality should be considered in future research. The over-representation of women in  
27  
28 the included studies may have influenced the findings, potentially skewing them towards  
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30 experiences more characteristic of women and limiting generalisability to other groups.  
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32 Additionally, there is a risk of selection bias, as individuals with negative experiences of  
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34 mental health services may be more likely to participate in this type of research. As a  
35  
36 result, the findings may overemphasise adverse experiences and not fully reflect the  
37  
38 range of perspectives among late-diagnosed autistic adults. Finally, this review only used  
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40 qualitative data, possibly excluding valuable insights from quantitative studies.  
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### 6. Conclusion

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54 This review highlights the challenges faced by late diagnosed autistic adults in accessing mental  
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56 health support, emphasizing the need for professionals to better understand and cater to the  
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## Mental Health Support Experiences of Late Diagnosed Autistic Adults

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4 specific needs of this population. The lack of recognition and appropriate support for autistic  
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6 individuals can lead to negative experiences within mental health services, underscoring the  
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8 importance of specialised training for professionals and post-diagnostic support to improve  
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10 mental health outcomes for late diagnosed autistic adults.  
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