Effectiveness of primary care psychological therapy services for treating depression and anxiety in autistic adults in England: a retrospective, matched, observational cohort study of national health-care records

Céline El Baou, Georgia Bell, Rob Saunders, Joshua E J Buckman, William Mandy, Dave Dagnan, Elizabeth O'Nions, Richard Pender, Henry Clements, Stephen Pilling, Marcus Richards, Amber John, Joshua Stott**

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*Joint senior authors

Adapt Lab (C El Baou MSc, G Bell MSc, R Saunders PhD, E O'Nions PhD, A John PhD, Prof J Stott DClinPsy PhD), **and CORE Data Lab, Centre for Outcomes Research and Effectiveness** (R Saunders, J E J Buckman DClinPsy PhD, Prof S Pilling PhD), **Research Department of Clinical, Educational and Health Psychology** (C El Baou, G Bell, R Saunders, E O'Nions, A John, Prof J Stott, Prof W Mandy DClinPsy PhD, R Pender DClinPsy, H Clements DClinPsy PhD), **University College London, London, UK; iCope, Camden & Islington NHS Foundation Trust, St Pancras Hospital, London, UK** (J E J Buckman); **Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust, Community Learning Disability Services, Lillyhall, Workington, UK** (Prof D Dagnan PhD); **Camden & Islington NHS Foundation Trust, St Pancras Hospital, London, UK** (Prof S Pilling); **MRC Unit for Lifelong Health and Ageing at UCL, University College London, London, UK** (Prof M Richards PhD)

Correspondence to: Céline El Baou, Adapt Lab, Research Department of Clinical, Educational and Health Psychology, University College London, London WC1E 7HB, UK
celine.el.baou.20@ucl.ac.uk

Summary

Background Autistic adults report a higher prevalence of anxiety and depression than adults without identified autism but have poorer access to appropriate mental health care. Evidence-based psychological therapies are recommended in treatment guidelines for autistic adults, but no study has investigated their effectiveness in large samples representative of the autistic population accessing routine care. This study aimed to examine therapy outcomes for autistic adults in a primary care service.

Methods In this retrospective, matched, observational cohort study of national health-care records, we used the MODIFY dataset that used linked electronic health-care records, including national data, for individuals who accessed psychological therapy in primary care in Improving Access to Psychological Therapies (IAPT) services in 211 clinical commissioning group areas in England, UK. All adults aged 18 years or older who had completed a course of IAPT in 2012–19 were eligible, and were propensity score matched (1:1) with a comparison group without identified autism. Exact matching was used, when possible, for a range of sociodemographic factors. Primary outcomes were routine metrics that have been nationally defined and used to evaluate IAPT treatments: reliable improvement, reliable recovery, and reliable deterioration. Secondary outcomes were calculated pre–post treatment changes in scores for Patient Health Questionnaire-9, Generalised Anxiety Disorder Assessment-7, and Work and Social Adjustment Scale measures. Subgroup analyses investigated differential effects across a range of sociodemographic factors.

Findings Of 2 515 402 adults who completed at least two sessions of IAPT in 2012–19, 8761 had an autism diagnosis (5054 [57·7%] male and 3707 [42·3%] female) and 1 918 504 did not (631 606 [32·9%] male and 1 286 898 [67·0%] female). After propensity score matching, 8593 autistic individuals were matched with an individual in the comparison group. During IAPT treatment, symptoms of depression and generalised anxiety disorder decreased for most autistic adults, but symptoms were less likely to improve in the autism group than in the comparison group (4820 [56·1%] of 8593 autistic adults had reliable improvement *vs* 5304 [61·7%] of 8593 adults in the matched group; adjusted odds ratio [OR_{adj}] 0·75, 95% CI 0·70–0·80; p<0·0001) and symptoms were more likely to deteriorate (792 [9·2%] *vs* 619 [7·2%]; OR_{adj} 1·34, 1·18–1·48; p<0·0001). In the comparison group, improved outcomes were associated with employment and belonging to a higher socioeconomic deprivation category, but this was not the case for autistic adults.

Interpretation Evidence-based psychological therapy for depression or anxiety might be effective for autistic adults but less so than for adults without identified autism. Treatment moderators appear different for autistic individuals, so more research is needed to allow for better targeted and personalised care.

Funding Alzheimer's Society.

Introduction

Autism spectrum disorder (ie, autism) is a neurodevelopmental condition, characterised by specific experiences in social communication and interaction, with specialised, focused, or intense interests and behaviours.[1] 1–2% of the population in England are autistic.[2] Autistic adults have a high chance of developing mental health difficulties. In this Article, we use identity-first language rather than person-first language; we acknowledge and respect the different views on this use within the autism community and among professionals. These individuals are disproportionately affected by anxiety and depression, which are leading causes of disability and health-related burden worldwide.[3] Some estimates suggest autistic adults have a point prevalence of 27% for anxiety and 23% for depression,[3] compared with 5·9% for anxiety and 3·3% for depression in the general population.[4] Conversely, autistic adults

Research in context

Evidence before this study

Treatment guidelines recommend that autistic adults are treated in primary care psychological therapy services when experiencing depression or anxiety. However, the effectiveness of psychological therapies provided in such routine care settings remains to be examined. We searched PubMed for papers in English published from database inception to Aug 1, 2023, using the title or abstract search terms: (anxi* OR depress*) AND (therap* OR interven*) AND (autis* OR Asperger*) AND ((primar* NEAR care*) OR routine* OR (service* NEAR (mental OR psycholog*))). We identified 84 papers; however, after screening of the abstracts, there were no relevant studies investigating therapy for autistic adults in a routine clinical setting.

Added value of this study

To our knowledge, this is the first study to evaluate the effectiveness of mental health interventions in a large cohort of autistic adults in a routine clinical setting. Using routinely collected data from 8761 autistic adults who completed a course of psychological therapy in Improving Access to Psychological Therapies services in England in 2012–19, we found that depression and anxiety symptoms reduce after a course of psychological therapy in primary care. However, autistic adults were less likely to experience reliable reduction in or recovery from anxiety or depression symptoms than the comparison group, and autistic adults were more likely to experience a deterioration in their mental health. Subgroup analyses also provided novel findings; factors associated with better outcomes in adults without identified autism (ie, employment and low socioeconomic deprivation) might not have the same moderating effect on outcomes for autistic adults.

Implications of all the available evidence

This study builds on existing findings from small randomised controlled trials by providing evidence in naturalistic settings that psychological therapy for depression or anxiety might improve mental health of autistic adults. Our findings have important clinical and research implications. Given that the prevalence of mental health problems in autistic adults is higher than in adults without identified autism, we suggest access should be improved to primary care services for autistic adults and further research should be done to see whether interventions can be adapted to improve their outcomes.

report more unmet needs than adults without identified autism in terms of mental health service provision.[5] Addressing this mental health crisis for autism has been deemed a priority concern by WHO[6] and the autism community.[7]

For autistic adults with co-occurring depression or anxiety, the most recent systematic review found that evidence-based psychological therapy, such as cognitive-behavioural therapy (CBT) and mindfulness therapy, might be useful in managing mental health symptoms, especially when such treatments are adapted to their specific needs.[8] However, these reviews had small sample sizes with imprecise estimates of efficacy and a low certainty of evidence. Furthermore, to our knowledge, no previous study has examined the outcomes of routinely delivered psychological therapy for common mental health problems in autistic adults in primary or community care settings. Most psychological therapy interventions in the UK and elsewhere are delivered in such settings,[9] and many treatment guidelines recommend that autistic adults should be offered therapy in primary or community services.[10] Consequently, understanding the effectiveness of psychological therapy is important to inform the implementation of these recommendations. Evaluating the effectiveness is also essential to understand whether primary or community services can respond to the considerable mental health needs of autistic adults, or whether (further) adaptations might be needed.

In line with guidance for evaluating complex interventions from the Medical Research Council, this study uses a naturalistic design to assess psychological therapy outcomes for autistic adults attending a National Health Service (NHS) primary and community care psychological therapy programme (Improving Access to Psychological Therapies [IAPT] also known as NHS Talking Therapies for Anxiety and Depression). These services are recommended in national guidelines as the first-line treatment for common mental health difficulties[10] and offer various evidence-based psychological therapies delivered by trained professionals (appendix p 12).

See Online for appendix

This study aims to (1) examine the change in symptoms of depression and anxiety after a course of psychological therapy (ie, IAPT) in a large sample of autistic adults; (2) investigate how therapy outcomes differ for autistic adults compared with adults without identified autism; and (3) evaluate whether therapy outcomes differ across subgroups according to sociodemographic factors.

Methods

Study design and data sources

In this retrospective, matched, observational cohort study, we used the MODIFY dataset[11] that used electronic health-care records of patients who received psychological therapy in any IAPT service across all 211 clinical commissioning group areas in England, UK, in 2012–19.[12] To identify individuals with an autism diagnosis in the IAPT database, records were linked with three databases in which this information was available: the Hospital Episode Statistics (HES) data, the Mental Health Services Dataset (MHSDS), and HES–Office for National

For more on **guidance for evaluating complex interventions from the Medical Research Council** see https://www.ukri.org/wp-content/uploads/2021/11/NERC-301121-NaturalExperimentsGuidance.pdf

Statistics mortality data, using a key provided by NHS Digital.[12–15] The MODIFY dataset included information on demographic characteristics, psychological therapy factors, and other health-care variables for patients across England (appendix p 4). Data on current self-reported phenotypical gender (ie, male, female, not known, or not specified) was collected in IAPT therapy at time of referral.

Non-identifiable information was provided by NHS Digital with a legal basis for anonymisation; therefore, the study did not require research ethics committee review as per the Governance Arrangements of Research Ethics Committees. This study followed the RECORD guidelines.[16]

Study participants

All adults aged 18–110 years, who completed at least two sessions of IAPT between 2012 and 2019, as per NHS established evaluation criteria[12] and previous research,[17] and had a record in IAPT and a linked record in HES or MHSDS were eligible. Therapy within IAPT included evidence-based psychological therapies as recommended in national guidelines from the National Institute for Health and Care Excellence, following a stepped-care model in which the intensity of interventions depended on the clinical presentation of the service user.[12] These guidelines recommended autism-specific adaptations for interventions targeting co-occurring mental health difficulties,[18] such as the use of more written, concrete, and visual material. During the study, when autism diagnosis status was known or disclosed (or both), some IAPT therapists reported adapting their practice when working with autistic adults. The actual proportion of autistic people who received adaptations is unknown.[19]

When participants had more than one episode of treatment in an IAPT service during the study, only data for the first course of treatment were used. Standard exclusion criteria were not meeting clinical cutoff for depression or anxiety, having a primary diagnosis for which there was no evidence-based psychological therapy offered in IAPT, still in treatment, and missing data for the Patient Health Questionnaire (PHQ)-9 and Generalised Anxiety Disorder Assessment (GAD)-7 measure. Previous research has found the effect of excluding missing data might be negligible when only a small amount of data is missing.[20] Records were also excluded when recording errors were detected.

For a small group of individuals, Anxiety Disorder Specific Measures (ADSM) had been used to measure improvement in anxiety outcomes in place of GAD-7. For consistency, these records were excluded from the primary analyses, but included in sensitivity analyses.

Procedures

Autism status was identified using diagnostic codes entered in the HES and MHSDS databases, according to ICD-10 using codes F84.0, F84.1, and F84.5 as per previous research.[21] To reflect the lifelong characteristics of autism, diagnosis codes were considered regardless of their temporal relationship to IAPT referral.

Outcomes were measures commonly used in services. Depression and anxiety measures were taken from the IAPT dataset before and after therapy. Caseness thresholds (ie, a score above which clinical depression and anxiety are defined) were those usually used in research and practice.[12] Depression was assessed using PHQ-9[22] with a caseness threshold score of 10. This questionnaire was validated and found to have acceptable psychometric properties in cohorts of autistic people with heterogeneous autistic characteristics and co-occurring intellectual disabilities.[23] Caseness refers to a level of symptoms likely to be sufficient for meeting diagnostic criteria for the measured mental health problem. Generalised anxiety disorder was assessed using GAD-7, with a caseness threshold score of 8.[24] Because changes in work and social functioning might occur independently from changes in symptoms of depression and anxiety, functional impairment was measured using the Work and Social Adjustment Scale (WSAS)[25] and analysed separately. GAD-7 and WSAS were previously used in autistic populations,[26,27] but their psychometric properties have not been fully validated in this population, and the extent of their validity in representative autistic cohorts is unknown.

Outcomes

Nationally defined outcome metrics for IAPT were derived from the symptom measures above,[12] and have been widely used in previous research.[17] These primary outcomes were reliable improvement, reliable recovery, and reliable deterioration. Reliable improvement was a reduction in symptoms of depression or anxiety from the first to last attended treatment session that exceeded the threshold for error of measurement on the corresponding symptom scale (≥6 points on PHQ-9, ≥4 points on GAD-7). Assessing recovery was an intermediate step in defining reliable recovery. Recovery was ending treatment below the threshold for caseness on measures of depression and anxiety. Reliable recovery was a reliable improvement plus recovery as previously defined. Reliable deterioration was an increase in depression or anxiety symptoms from the first to last attended treatment session by at least the magnitude of the threshold for the error of measurement (see reliable improvement).

Secondary outcomes included pre–post change in measures of depression (PHQ-9), generalised anxiety disorder (GAD-7), and work and social functioning (WSAS).[25] For a change in work and social functioning, data were available for a subset of individuals only, with an available sample size sufficient to conduct these analyses. A range of covariates known to be associated with therapy outcomes were included in analyses (appendix p 5).

Statistical analysis

We present summary statistics of demographic characteristics and treatment factors for adults with and without an autism diagnosis. Sample representativeness was also assessed by comparing demographic characteristics to available data on national autism prevalence. Missing data for categorical variables were handled by adding a missing category. There were no missing data for continuous covariates. We investigated differences between pre-treatment and post-treatment in symptoms of depression and anxiety in the autistic group, using paired sample *t* tests. Given the absence of a comparison group of autistic adults not receiving IAPT therapy, effect sizes identified from a systematic review of randomised controlled trials evaluating psychosocial interventions[8] in autistic adults with co-occurring mental health difficulties were used to contextualise the findings. We thus calculated Cohen's $d_{average}$ adapted for within-subject design for each identified group (treatment or control) in each randomised controlled trial.

We explored whether an autism diagnosis (*vs* no diagnosis) was associated with therapy outcomes. Logistic regression models were used for primary outcomes and linear regression models were used for secondary outcomes. Models were run in the following sequence: (1) included autistic group or comparison group; (2) additionally adjusted for clinical and sociodemographic covariates; (3) additionally adjusted for IAPT treatment factors; and (4) re-run using a propensity score matched[28] sample to account for differences between the autistic group and the comparison group, and as recommended when the size of the comparison group far exceeds that of the treatment group.[29] In this last analysis, adults with an autism diagnosis were matched with control participants without identified autism using psmatch2.[30] The propensity score was estimated using logistic regression, including all factors possibly associated with the outcomes as covariates. Exact matching was used for categorical covariates, and a calliper was set to 0·1 for propensity score matching. When a control was identified as an appropriate match for more than one participant in the autistic group, they were weighted and used in the analysis (maximum weight=2). Model 4, fully adjusted after matching, was considered the primary model.

We investigated whether previously listed covariates were associated with different therapy outcomes for autistic adults compared to adults without identified autism. We tested for this association by checking for an interaction between the autistic group and each demographic or clinical factor in the fully adjusted models in the matched cohort and full cohort and comparing primary outcomes between subgroups.

Two sensitivity analyses were conducted by re-running analyses: one including records in which ADSM measures were used for anxiety symptoms, and one including a random intercept to consider potential clustering effect by NHS clinical commissioning group. All analyses were done using STATA, version 17.

Role of the funding source

The funder of the study had no role in the study design, data collection, data analysis, data interpretation, or writing of the report.

Results

Data were available for 2 515 402 people from the MODIFY dataset who completed at least two sessions of IAPT therapy in 2012–19 (figure 1). 8761 adults had an autism diagnosis code and 1 918 504 did not. Before propensity score matching, compared with adults without identified autism, autistic adults were more likely to be male, aged 18–24 years, unemployed, and have intellectual disabilities (table 1). IAPT treatment-related factors were similar between groups in terms of presenting problem, year of treatment, number of sessions, and waiting times between referral, assessment, and treatment. Autistic

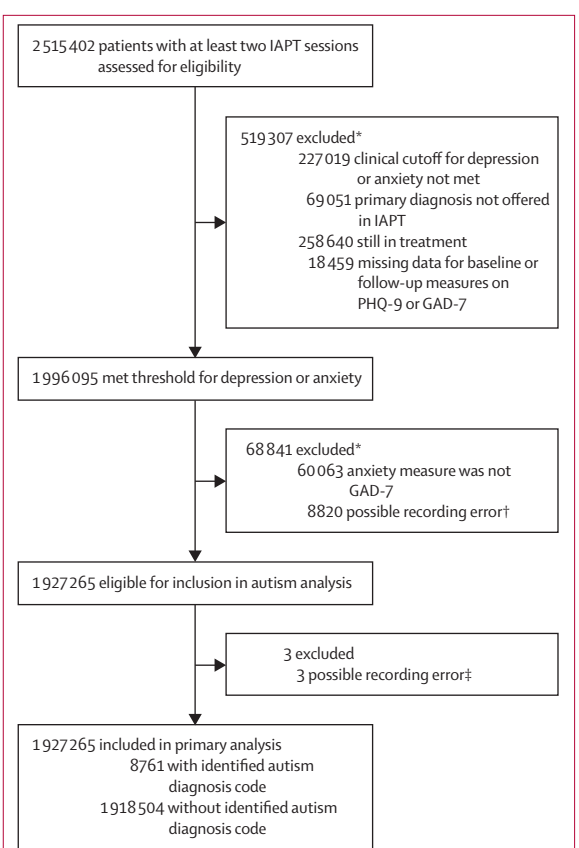

Figure 1: **Study profile**
GAD-7=Generalised Anxiety Disorder Assessment-7. IAPT=Improving Access to Psychological Therapies. PHQ-9=Patient Health Questionnaire-9. *Participants might have multiple exclusion criteria so data might not add up. †Recording errors were people older than 110 years (n=5), date of assessment before referral (n=1783), and missing gender (n=3). ‡Recording error was date of first autism diagnosis before date of birth.

adults were less likely to complete treatment than adults without identified autism, and autistic adults were more likely to receive high-intensity sessions, be referred on to further services, and for IAPT services to be considered unsuitable than were adults without identified autism.

After propensity score matching, 8593 autistic individuals were matched with a person with similar characteristics (appendix p 7). Demographic and baseline characteristics were similar in both groups after matching.

Of 1 927 265 individuals included in the primary analysis, 8761 (0·45%) were autistic. This proportion was compared with the proportion of autistic adults that would be expected in IAPT services (1·1–2·4%) on the basis of national prevalence estimates of depression and anxiety in the general population and among autistic adults. We

	Before matching		After matching	
	Autism diagnosis (n=8761)	No identified autism diagnosis (n=1 918 504)	Autism diagnosis (n=8593)	No identified autism diagnosis (n=8593)
Demographics				
Age at referral, years	30·5 (12·1); 18–82	40·6 (14·9); 18–102	30·4 (12·0); 18–82	31·6 (12·4; 18–93
Age group				
18–24 years	3829 (43·7%)	297 460 (15·5%)	3740 (43·5%)	3740 (43·5%)
25–44 years	3582 (40·9%)	882 412 (46·0%)	3558 (41·4%)	3558 (41·4%)
45–64 years	1260 (14·4%)	606 185 (31·6%)	1208 (14·1%)	1208 (14·1%)
≥65 years	90 (1·0%)	132 447 (6·9%)	87 (1·0%)	87 (1·0%)
Ethnicity				
White	7407 (84·5%)	1 567 482 (81·7%)	7301 (85·0%)	7301 (85·0%)
Mixed	177 (2·0%)	37 182 (2·0%)	170 (2·0%)	170 (2·0%)
Asian	164 (1·9%)	79 586 (4·2%)	148 (1·7%)	148 (1·7%)
Black	111 (1·3%)	48 290 (2·5%)	98 (1·1%)	98 (1·1%)
Missing or other	902 (10·3%)	185 964 (9·7%)	879 (10·2%)	879 (10·2%)
Gender				
Male	5054 (57·7%)	631 606 (32·9%)	4974 (57·9%)	4974 (57·9%)
Female	3707 (42·3%)	1 286 898 (67·0%)	3619 (42·1%)	3619 (42·1%)
IMD quintile				
1 (most deprived)	2191 (25·0%)	416 831 (21·7%)	2117 (24·6%)	2117 (24·6%)
2	1933 (22·1%)	410 478 (21·4%)	1897 (22·1%)	1897 (22·1%)
3	1687 (19·3%)	374 166 (19·5%)	1663 (19·4%)	1663 (19·4%)
4	1427 (16·3%)	342 245 (17·8%)	1417 (16·5%)	1417 (16·5%)
5 (least deprived)	1218 (13·9%)	310 030 (16·2%)	1197 (13·9%)	1197 (13·9%)
Missing	305 (3·5%)	64 754 (3·4%)	302 (3·5%)	302 (3·5%)
Employment status before therapy				
Employed	2709 (30·9%)	1 049 968 (54·7%)	2691 (31·3%)	2691 (31·3%)
Unemployed and job seeking	1869 (21·3%)	211 239 (11·0%)	1792 (20·9%)	1792 (20·9%)
Unemployed and not job seeking	2051 (23·4%)	390 594 (20·4%)	2028 (23·6%)	2028 (23·6%)
Chronic illness or receiving benefits	1447 (16·5%)	146 635 (7·6%)	1424 (16·6%)	1424 (16·6%)
Missing	685 (7·8%)	120 068 (6·3%)	658 (7·7%)	658 (7·7%)
Clinical measures				
Depression symptoms pre-treatment (PHQ-9)	16·8 (5·5); 0–27	15·9 (5·5); 0–27	16·8 (5·5); 0–27	16·8 (5·4); 0–27
Anxiety symptoms pre-treatment (GAD-7)	14·8 (4·4); 0–21	14·3 (4·4); 0–21	14·8 (4·3); 0–21	14·7 (4·3); 0–21
Social functioning pre-treatment (WSAS)	20·5 (9·4); 0–40	18·7 (9·1); 0–40	20·5 (9·4); 0–40	19·9 (9·0); 0–40
Intellectual disabilities	387 (4·4%)	2244 (0·1%)	342 (3·9%)	222 (2·6%)
Psychotropic medication				
Yes	4415 (50·4%)	825 930 (43·1%)	4326 (50·3%)	4326 (50·3%)
No	3359 (38·3%)	907 296 (47·3%)	3317 (38·6%)	3317 (38·6%)
Missing	987 (11·3%)	185 378 (9·7%)	950 (11·1%)	950 (11·1%)
Chronic illness (as self-reported in IAPT)				
Yes	4114 (47·0%)	443 409 (23·1%)	2419 (28·2%)	2376 (28·2%)
No	2454 (28·0%)	1 064 928 (55·5%)	4067 (47·3%)	4140 (48·2%)
Missing	2193 (25·0%)	410 167 (21·4%)	2107 (24·5%)	2077 (24·2%)

(Table 1 continues on next page)

	Before matching		After matching	
	Autism diagnosis (n=8761)	No identified autism diagnosis (n=1 918 504)	Autism diagnosis (n=8593)	No identified autism diagnosis (n=8593)
(Continued from previous page)				
IAPT treatment factors				
Diagnosis category (as assessed in IAPT)				
Depression	2277 (26·0%)	570 719 (29·8%)	2201 (25·6%)	2263 (26·3%)
Anxiety disorders	3550 (40·5%)	793 804 (41·4%)	3509 (40·1%)	3445 (40·1%)
Mixed anxiety and depressive disorder	1562 (17·8%)	326 578 (17·0%)	1547 (18·0%)	1535 (17·9%)
GAD	1011 (11·5%)	292 384 (15·2%)	995 (11·6%)	940 (10·9%)
OCD	222 (2·5%)	22 488 (1·2%)	219 (2·6%)	134 (10·9%)
PTSD	164 (1·9%)	39 620 (2·1%)	160 (1·9%)	243 (2·9%)
Phobic anxiety and panic	570 (6·5%)	106 523 (5·6%)	567 (6·7%)	573 (6·7%)
Other anxiety disorder	21 (0·2%)	6211 (0·3%)	21 (0·2%)	20 (0·2%)
Missing	2934 (33·5%)	553 981 (28·9%)	2883 (33·6%)	2885 (33·6%)
Year of treatment				
2012	342 (3·9%)	62 949 (3·3%)	287 (3·3%)	276 (3·2%)
2013	1119 (12·8%)	222 034 (11·6%)	1111 (12·9%)	1137 (13·2%)
2014	1140 (16·1%)	295 557 (15·4%)	1387 (16·1%)	1419 (16·5%)
2015	1169 (18·5%)	337 541 (17·6%)	1593 (18·5%)	1606 (18·7%)
2016	1481 (16·9%)	331 451 (17·3%)	1465 (17·1%)	1486 (17·3%)
2017	1323 (15·1%)	308 609 (16·1%)	1302 (15·2%)	1243 (14·5%)
2018	1232 (14·1%)	298 094 (15·5%)	1213 (14·1%)	1183 (13·8%)
2019	235 (2·7%)	62 269 (3·2%)	235 (2·7%)	243 (2·8%)
Post-therapy completion status				
Completed	3595 (41·0%)	916 115 (47·8%)	3547 (41·3%)	3501 (40·7%)
Dropped out of treatment	1886 (21·5%)	419 372 (21·9%)	1863 (21·7%)	1858 (21·7%)
Service not suitable	183 (2·1%)	19 935 (1·1%)	179 (2·1%)	184 (2·1%)
Declined	239 (2·7%)	53 036 (2·8%)	235 (2·7%)	233 (2·7%)
Started therapy but referred on to other service	612 (7·0%)	66 005 (3·4%)	603 (7·0%)	601 (7·0%)
Missing	2246 (25·6%)	444 041 (23·2%)	2166 (25·2%)	2216 (25·6%)
Number of sessions*	6·5 (4·6); 2–23	6·2 (4·2); 2–23	6·5 (4·6); 2–23	6·3 (4·6); 2–23
Time between referral and assessment, weeks*	3·8 (4·8); 0–28	3·2 (4·4); 0–28	3·8 (4·8); 0–28	3·8 (5·2); 0–28
Time between assessment and treatment, weeks*	10·9 (11·9); 0–36	9·4 (10·9); 0–36	10·8 (11·8); 0–36	10·9 (12·1); 0–36
Average time between sessions, weeks	2·9 (2·0); 0·14–11	2·8 (1·8); 0·14–11	2·9 (2·0); 0·14–11	2·9 (2·0); 0·1–11
Participants with six or more low-intensity sessions	1079 (12·3%)	339 769 (17·7%)	1066 (12·4%)	991 (11·5%)
Participants with six or more high-intensity sessions	2458 (28·1%)	467 776 (24·4%)	2426 (28·2%)	2419 (28·2%)

Data are mean (SD); range or n (%). GAD=generalised anxiety disorder. GAD-7=Generalised Anxiety Disorder Assessment-7. IAPT=Improving Access to Psychological Therapies. IMD=Index of Multiple Deprivation. OCD=obsessive compulsive disorder. PHQ-9=Patient Health Questionnaire-9. PTSD=post-traumatic stress disorder. WSAS= Work and Social Adjustment Scale. *To reduce the effect of extreme values, variables were winsorised at the top 99% percentile.

Table 1: **Demographics and baseline characteristics**

found that the autistic population was under-represented by approximately 2·4–5·3 times in our study. Similarly, when comparing prevalence estimates that would be expected in a population of autistic adults with mental health difficulties, we found that men, older adults (aged ≥65 years), and adults with intellectual disabilities were under-represented (appendix p 14).

Symptoms of depression and generalised anxiety disorder improved for autistic adults during IAPT therapy. Mean change in depression (PHQ-9) and anxiety (GAD-7) scores, and the proportion of individuals with reliable recovery, improvement, and deterioration are provided in table 2. Pre–post therapy effect sizes were moderate for depression (Cohen's $d_{average}$=–0·71, 95% CI –0·74 to –0·68) and anxiety (–0·78, 95% CI –0·80 to –0·75) in autistic adults.

For depression symptoms, pre–post therapy effect sizes were slightly smaller than the effect sizes observed in randomised controlled trials of interventions adapted for autistic adults, such as adapted mindfulness therapy (Cohen's $d_{average}$=–0·82, –1·46 to –0·18),[31] adapted guided self-help (–0·94, –1·45 to –0·43),[32] and adapted group CBT (–1·02, –1·62 to –0·42).[33] For anxiety symptoms, IAPT effect sizes were similar to or higher

	Before matching		After matching	
	Autism diagnosis (n=8761)	No identified autism diagnosis (n=1 918 504)	Autism diagnosis (n=8593)	No identified autism diagnosis (n=8593)
Primary outcomes				
Reliable improvement	4924 (56·2%)	1 309 005 (68·2%)	4820 (56·1%)	5304 (61·7%)
Recovery	2883 (32·9%)	934 173 (48·7%)	2802 (32·6%)	3382 (39·4%)
Reliable recovery	2718 (31·0%)	890 906 (46·4%)	2639 (30·7%)	3242 (37·8%)
Deterioration	810 (9·3%)	110 101 (5·7%)	792 (9·2%)	619 (7·2%)
Secondary outcomes				
PHQ-9				
Baseline	16·8 (5·5)	15·9 (5·5)	16·8 (5·5)	16·8 (5·3)
After treatment	12·3 (7·2)	9·9 (6·9)	12·3 (7·1)	11·3 (7·2)
Change	−4·5 (6·7)	−6·2 (6·6)	−4·5 (6·7)	−5·5 (6·7)
GAD-7				
Baseline	14·8 (4·4)	14·3 (4·4)	14·8 (4·4)	14·8 (4·3)
After treatment	10·7 (6·1)	8·9 (6·0)	10·7 (6·1)	9·9 (6·1)
Change	−4·1 (5·9)	−5·5 (5·9)	−4·1 (5·9)	−4·8 (5·9)
WSAS				
Baseline	20·5 (9·4); n=5470	18·7 (9·1); n=1 265 609	20·6 (9·4); n=5408	19·9 (9·0); n=5404
After treatment*	NA	NA	NA	NA
Change	−3·7 (9·7); n=5435	−5·8 (9·5); n=1 259 651	−3·8 (9·7); n=5437	−4·8 (9·7); n=5376

Data are n (%) or mean (SD). Recovery, on its own, was not a primary outcome, but was an intermediate step in defining reliable recovery, which is a more stringent measure. It is presented only in descriptive statistics here. GAD-7=Generalised Anxiety Disorder Assessment-7. NA=not available. PHQ=Patient Health Questionnaire. WSAS=Work and Social Adjustment Scale. *Data were not extracted from the dataset.

Table 2: **Clinical measures and outcomes**

	Model 1: full sample (unadjusted)			Model 2: full sample (adjusted)*			Model 3: full sample (adjusted)†			Model 4: propensity score matched (adjusted)‡		
	n	OR or adjusted mean difference (95% CI)	p value	n	OR or adjusted mean difference (95% CI)	p value	n	OR or adjusted mean difference (95% CI)	p value	n	OR or adjusted mean difference (95% CI)	p value
Primary outcomes												
Reliable improvement	1 927 265	0·60 (0·57 to 0·62)	<0·0001	1 927 265	0·78 (0·75 to 0·82)	<0·0001	1 927 265	0·76 (0·72 to 0·79)	<0·0001	17 186	0·75 (0·70 to 0·80)	<0·0001
Reliable recovery	1 927 265	0·52 (0·50 to 0·54)	<0·0001	1 927 265	0·70 (0·70 to 0·77)	<0·0001	1 927 265	0·71 (0·68 to 0·75)	<0·0001	17 186	0·68 (0·63 to 0·73)	<0·0001
Reliable deterioration	1 927 265	1·67 (1·56 to 1·80)	<0·0001	1 927 265	1·38 (1·28 to 1·48)	<0·0001	1 927 265	1·34 (1·24 to 1·45)	<0·0001	17 186	1·34 (1·18 to 1·48)	<0·0001
Secondary outcomes												
PHQ-9 change	1 927 265	−1·69 (−1·82 to −1·55)	<0·0001	1 927 265	−1·06 (−1·18 to −0·93)	<0·0001	1 927 265	−1·00 (−1·12 to −0·89)	<0·0001	17 186	−0·97 (−1·15 to −0·80)	<0·0001
GAD-7 change	1 927 265	−1·53 (−1·66 to −1·41)	<0·0001	1 927 265	−0·79 (−0·90 to −0·68)	<0·0001	1 927 265	−0·76 (−0·86 to −0·67)	<0·0001	17 186	−0·80 (−0·96 to −0·65)	<0·0001
WSAS change	1 265 086	−2·11 (−2·37 to −1·86)	<0·0001	1 265 086	−1·22 (−1·48 to −0·97)	<0·0001	1 265 086	−1·20 (−1·43 to −0·95)	<0·0001	10 750	−1·01 (−1·37 to −0·66)	<0·0001

GAD-7=Generalised Anxiety Disorder Assessment-7. IAPT=Improving Access to Psychological Therapies. IMD=Index of Multiple Deprivation. OR=odds ratio. PHQ-9=Patient Health Questionnaire-9. WSAS=Work and Social Adjustment Scale. *Adjusted for gender, ethnicity, employment status, case of long-term condition, psychotropic medication, diagnosis category, IMD quintile, intellectual disability, year of first appointment, age at referral, baseline PHQ-9, and baseline GAD-7. †Adjusted for gender, ethnicity, employment status, case of long-term condition, psychotropic medication, diagnosis category, IMD quintile, intellectual disability, year of first appointment, age at referral, baseline PHQ-9, baseline GAD-7, waiting time from referral to assessment, waiting time from assessment to treatment, year of appointment, number of low-intensity sessions, number of high-intensity sessions, reason for ending treatment, and frequency of sessions. ‡The propensity score was estimated using logistic regression using age group, gender, ethnicity, employment status, case of long-term condition, psychotropic medication, and IMD quintile as categorical covariates and year of first appointment, baseline PHQ-9, baseline GAD-7, intellectual disability, waiting time from referral to assessment, and waiting time from assessment to treatment as continuous covariates. The propensity score was estimated using logistic regression, including all factors possibly associated with the outcomes as covariates. Exact matching was used for all categorical covariates and a calliper was set to 0·1 for propensity score matching.

Table 3: **Primary and secondary outcomes after IAPT in individuals with an autism diagnosis versus individuals without identified autism**

than effect sizes for adapted mindfulness therapy[31] (–0·64, –1·28 to –0·01) and guided self-help[32] (–0·73, –1·23 to –0·23). For anxiety and depression, these effect sizes were higher than effect sizes observed in treatment as usual in the NHS,[32] and similar to or higher than effect sizes observed in waiting list controls.[31] Notably, sample sizes were substantially smaller in randomised trials (eg, 20 to 35 participants) than in our cohort, meaning that estimated effect sizes from these studies are more imprecise than those observed in our study. By comparison, IAPT estimates and their 95% CIs were all within the confidence limits of the results obtained in randomised controlled trials (appendix p 6).

Autistic adults were less likely to meet improvement and recovery criteria and were more likely to show a deterioration in their symptoms than adults without identified autism (table 3). For primary outcomes, we observed a significantly reduced likelihood of reliable improvement (odds ratio [OR] 0·75, 95% CI 0·70 to 0·80; p<0·0001), a significantly reduced likelihood of reliable recovery (OR 0·68, 0·63 to 0·73; p<0·0001), and a significantly increased likelihood of deterioration (OR 1·34, 1·18 to 1·48; p<0·0001) in adjusted analyses after matching (model 4). Recovery, on its own, was not a primary outcome and was only included in summary statistics to refer to targets mandated by the UK Government. For all secondary outcomes, we observed similar results, with smaller decreases in symptom scores in the autistic group than in the comparison group for the PHQ-9 score (adjusted mean difference –0·97, 95% CI –1·15 to –0·80), the GAD-7 score (–0·80, –0·96 to –0·65), and the WSAS score (–1·01, –1·37 to –0·66). For all outcomes, adjusted analyses before matching (models 2 and 3) or after matching (model 4) yielded similar estimates. Differences between the autistic group and comparison group were more salient in unadjusted analyses (model 1), suggesting they might be partly accounted for by sociodemographic differences observed between the groups.

Subgroup analyses suggested there were differences between the autistic group and the comparison group regarding the association between sociodemographic factors and therapy outcomes, with the most substantial differences observed regarding the deprivation index and employment status. Specifically, in the comparison group, a lower level of socioeconomic deprivation was associated with better outcomes than a higher level of socioeconomic deprivation. This association was not seen for autistic adults who showed similar outcomes regardless of level of deprivation (figure 2). In high levels of socioeconomic deprivation, autistic adults had lower odds of reliable improvement than the comparison group (OR 0·89, 95% CI 0·79–1·00), but also had slightly lower odds in the lowest socioeconomic deprivation category (OR 0·68, 0·58–0·79).

Being employed and not being autistic was also associated with improved outcomes compared with being unemployed or autistic. If employed, autistic adults had lower odds of reaching reliable improvement after therapy than the employed comparison group (OR 0·65, 0·58–0·72; figure 2). By contrast, if unemployed and seeking work, autistic adults had similar odds of reaching reliable improvement as did the comparison group (OR 0·95, 0·84–1·07).

The strength of the differences in outcomes between autistic and comparison groups did not seem to be affected by other factors. This similarity was applicable to gender (reliable improvement, $OR_{adjusted}$ 0·81 [95% CI 0·75–0·87] for male participants and 0·74 [95% CI 0·67–0·80] for female participants) and to other factors (ie, taking psychotropic medications, diagnosis of anxiety

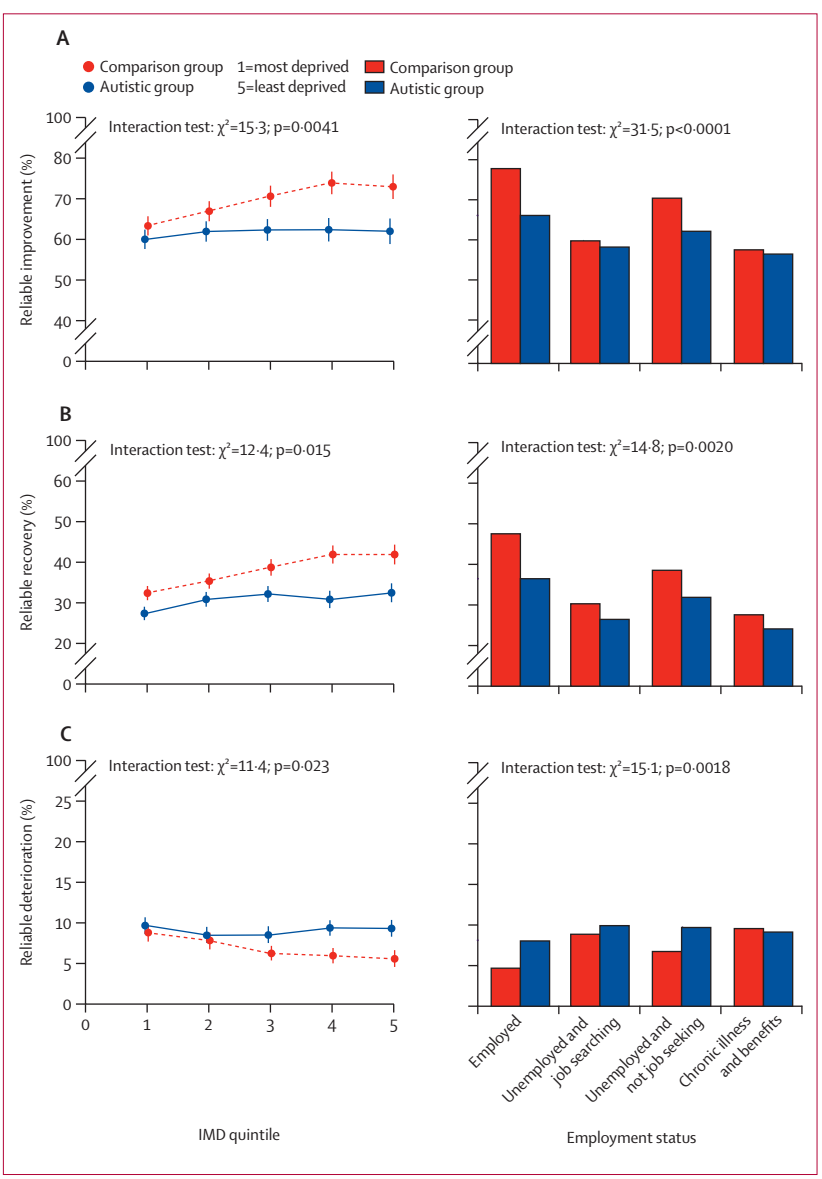

Figure 2: **Interaction tests and adjusted reliable improvement (A), recovery (B), and deterioration (C) rate by IMD quintile and employment status**
IMD=Index of Multiple Deprivation.

vs depression, and presence of a long-term condition; appendix p 10). Conducting subgroup analyses in the whole cohort led to similar observations to those in the matched cohort (appendix p 12). Sensitivity analyses yielded similar results to the main analyses (appendix pp 15–16).

Discussion

To our knowledge, this cohort study is the largest study so far of psychological therapy outcomes for autistic adults with depression or anxiety in a naturalistic setting. We found that autistic adults who completed a course of psychological therapy, on average, had clinically meaningful decreases in depression and anxiety symptoms. However, compared with a matched cohort of individuals without an identified autism diagnosis, outcomes in the autistic group were poorer. Depression and anxiety symptoms were significantly less likely to improve, and significantly more likely to deteriorate compared with the comparison group, despite the autistic group receiving more high-intensity treatment sessions. This study also highlighted subgroup differences. Employment and low social deprivation were associated with improved outcomes in the comparison group, but this was not the case in the autistic group, who generally had similar outcomes regardless of sociodemographic factors.

Pre–post treatment decreases in symptoms were similar to or smaller than those observed in randomised controlled trials of psychological interventions for anxiety and depression adapted for autistic adults,[31–33] and higher than those observed in control groups of these trials. Given the disparities in sample size and design between our study and randomised trials, such comparisons should be undertaken with caution.

Differential results across subgroups suggest that factors that lead to improved outcomes in the comparison group (low Index of Multiple Deprivation and being employed) might not have the same buffering effect on outcomes for autistic adults. These findings might reflect the poor access to services for autistic people who are unemployed or live in socially deprived areas, or that different mechanisms are involved for autistic people who receive treatment. This novel finding requires investigation to understand the mechanisms involved, as well as identify the prognostic indicators that might be used to inform the management of depression and anxiety and treatment decision making and adaptation for autistic adults.

There is substantial evidence that autistic adults face barriers to access psychological therapy services.[34] We estimated that autistic adults were under-represented by 2·4–5·3 times in our cohort compared with national prevalence estimates, with a disproportionate under-representation of groups who are already known to be under-represented in IAPT or are underdiagnosed with autism, such as older adults, adults from minoritised ethnicity groups, and adults with intellectual disability.[35,36] Therefore, it is highly probable that a disproportionate number of autistic adults experiencing depression or anxiety symptoms do not access services. Part of this misrepresentation could stem from the under-reporting of adult autism in the HES and MHSDS. These databases only include a small amount of historical data, and our sample of autistic adults only reflects the population of adults with a diagnosis accessing NHS secondary care services during the study period (2012–19).

Finally, although data were not available on autistic characteristics or support needs in our cohort, it is likely that improved access to therapy might be associated with specific autistic characteristics—ie, those who are more comfortable with verbal communication. Similarly, the under-representation of people with intellectual disabilities in the autistic cohort might be due to individuals not having a diagnosis code in their record, not completing questionnaires, or not being referred to services. It is necessary to better recognise the impact of intellectual disability on referral and engagement in therapy to understand the under-representation of this group within the autistic population in services. Furthermore, this study highlights the importance of gaining an understanding of the heterogeneity of autism in the context of accessing and receiving psychological interventions.

The strengths of this study include the large sample size, allowing precise estimates of effects, and well powered subgroup analyses. Our national dataset provides generalisable results, and by evaluating these routinely provided services, our results have immediate implications for implementation. The limitations include poor access to services and representativeness. The comparison group might have included undiagnosed adults due to trends in underdiagnosis of autism,[37] which could partly account for the attenuation of differences between groups after propensity score matching. It was also not possible to establish the extent (if any) of the adaptations made to clinical practice for autistic adults.[19] Moreover, the results rely on the assumption that outcomes established in the comparison group are transferrable to autistic populations. Although PHQ-9 has been validated for use in autistic adults, GAD-7 has not, and recent research suggests that anxiety might present differently in autistic adults.[38] It is unknown whether GAD-7 measures are reliable and valid for all autistic people and for those with intellectual disabilities. Depression in autistic adults might be caused by or associated with (or both) autistic burnout, a state of psychological and physical exhaustion and stress experienced because of the demands of an unaccommodating world.[39] It is therefore plausible that recovery does not look the same for autistic adults. More research is required to understand what represents a clinically meaningful change in symptoms for them in a primary care service such as IAPT,[8] as well as the most appropriate measures to evaluate it.

We have presented evidence that psychological therapies offered in primary and community care mental health services might help to alleviate symptoms of depression and anxiety in autistic adults who can access these services. However, they have poorer outcomes than adults without autism, and the recovery rate of 32·9% in autistic adults (table 2) is substantially less than the national target of 50% mandated by the UK Government.[12]

This study has also highlighted an under-representation of autistic adults in primary care psychological therapy services. This figure was even more substantial in autistic adults with intellectual disabilities. This under-representation calls for a need to improve access to psychological therapies for autistic adults, and to increase the understanding of influential factors, beyond what is already known about groups currently underserved in health-care services. Future research should also investigate whether specific autistic characteristics predict improved access to services to provide adaptations that increase accessibility to autistic people. Differences observed between autistic adults and adults without identified autism suggest that research is needed to understand whether there might be autism-specific causal or maintaining factors for anxiety and depression that warrant developing specific treatments to target these components.

Contributors

All authors conceptualised and designed the study. CEB, AJ, JS, RS, JEJB, and DD contributed to the methodology and formal analysis. CEB, AJ, and JS assessed and verified the underlying data reported in the manuscript. All authors contributed to the manuscript writing and reviewing, and approved the final version. All authors had full access to all data in the study and had final responsibility for the decision to submit for publication.

Declaration of interests

CEB, JS, GB, and AJ are supported by the Alzheimer's Society (AS-PG-18–013). JEJB was supported by Wellcome Trust (201292/Z/16/Z). MR was supported by the UK Medical Research Council (grants MC_UU_10019/1 and MC_UU_10019/3). CEB has been a statistical consultant to Eli Lilly and Company. EO'N, WM, and JS were supported by the Dunhill Medical Trust in unrelated projects. RS held an unrelated honorary position with NHS England, and their time was compensated through financial support to their employing institution. JS has been a consultant to NHS Wales Shared Services Partnership and is involved in unrelated research projects funded by National Institute for Health and Care Research (NIHR) Public Health Research, Economic and Social Research Council (ESRC), and NIHR. WM is involved in unrelated projects funded by ESRC, NIHR, Medical Research Council, and Autistica, and received consulting fees from Jessica Kingsley publishers, Jazz Pharma, and Just for Kids Law in unrelated projects. DD received funding in unrelated projects from NIHR. All other authors declare no competing interests.

Data sharing

All data used for this study are available on successful application to NHS Digital via the Data Access Request Service: https://digital.nhs.uk/services/data-access-request-service-dars. Data fields can be accessed via the NHS Digital data dictionary: https://www.datadictionary.nhs.uk/.

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