The economic benefits of ADIE treatment for autistic people with anxiety

Helen Hughson

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MQ Mental Health Research is an award-winning charity that supports much needed scientific research globally, to transform the lives of people affected by mental illness. Together with supporters and a global network of scientists, MQ works to create a world where mental illness is understood, effectively treated and prevented.

Thanks to Professor Hugo Critchley and his team, and to Dr Mark Taylor, for providing both additional data and invaluable context to the research discussed in this report.

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Summary

Autistic people can face a range of additional challenges in their everyday lives. One of the most serious of these is the far greater likelihood that they will experience a mental health condition. Eight in ten autistic adults in the UK are estimated to experience mental health conditions, compared to one in six non-autistic adults.

One of the most common mental health conditions among autistic people is Generalised Anxiety Disorder (GAD), which is characterised by persistent, excessive worry about many different things at once. The effects of a disorder like GAD can be debilitating for the people who experience it - and autistic people are around three times more likely to experience GAD than the general population. Of the 585,000 autistic adults in the UK, 105,000 (18%) experience GAD. This is three times the rate of the 5.9% of the general population diagnosed with the same.

As symptoms of anxiety can have a serious impact on a person's quality of life – through symptoms such as feelings of worry or restlessness, difficulty concentrating, difficulty sleeping, dizziness, and heart palpitations – it is imperative to find treatments that are better equipped to help autistic people manage their anxiety.

Yet autistic people experience a number of barriers to receiving the mental health support they need, and those barriers exist at every stage of the process of getting help, from diagnosis to treatment. For example, symptoms of anxiety can be wrongly attributed by medical professionals to autism rather than recognised as having a separate cause. Additionally, standard treatments for mental health conditions are not typically designed with autistic people in mind. Current NHS treatments for GAD are often language or emotion-based, such as talking or mindfulness therapies, which can directly conflict with the needs of some autistic people.

A new treatment could be effective in helping autistic people recover from GAD. 'Aligning Dimensions of Interoceptive Experience' (ADIE) was recently trialled in a study funded by MQ Mental Health Research. The treatment takes a different approach to the management of anxiety. It helps people recognise the physiological signals of anxiety more accurately. Since the

original study, it has also been trialled on other populations and has been developed into a format which can be administered almost entirely without clinical oversight.

If this treatment were rolled out to autistic people who might be both experiencing and likely to seek treatment for anxiety, the improved quality of life they might experience could be valued at as much as £125-£170 million (1,700-2,300 QALYs). For each person recovering this is equivalent to between £21-£28,000 of wellbeing benefits. It is also worth noting that ADIE treatment is now being trialled on other groups of people, and that the potential costs of rolling out this intervention are not covered in this report.

Various sensitivity scenarios indicate that the benefits could cover a much wider range, but still suggest a significant overall impact. Better data, and thus more research, would help to narrow the range and better quantify the potential benefits of new treatments. Social sector organisations like MQ Mental Health Research could potentially facilitate further economic evaluations by both helping researchers to fill in some of these gaps in their own work, and by drawing attention to the paucity of data on mental health in autistic people more broadly.

Nevertheless, the data suggests great potential for ADIE treatment to support as many as 6,000 autistic people in the UK to recover from GAD, and live fuller, happier lives.

ADIE treatment could help an additional

6,000

autistic people recover from GAD

Autistic adults are up to

3 times

more likely to experience GAD than the general population

At least

18%

of autistic people in the UK experience GAD

The annual potential benefits of rolling out ADIE treatment are valued at between

£125mn-£170mn

Introduction

In the UK, around 585,000 adults, or 1.1% of the adult population, have Autism Spectrum Disorder (ASD).[1] Autistic people process information and understand the world in a different way to non-autistic people. As a spectrum condition, autism covers a diverse range of needs and abilities: one person's experience of autism may look very different to another's. Nevertheless, some common manifestations of autism include difficulties with social interaction and communication, repetitive behaviour, intense focus on particular aspects of life, and over- or under-sensitivity to stimuli such as light or sound.[2]

WHO definition of Autism Spectrum Disorder

*"Autism spectrum disorder is characterised by persistent deficits in **the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are** clearly atypical or excessive for the individual's age and sociocultural context…*

*"**Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the** individual's functioning observable in all settings …"*[3]

- World Health Organisation,
International Classification of Diseases 11th Revision

In addition to processing information and understanding the world differently to non-autistic people, autistic people are also much more likely

[1] The National Institute for Health and Care Excellence (NICE), Autism in adults: How common is it? Version: 05/2020. Accessed 29 January 2024.
[2] MQ Mental Health Research, www.mqmentalhealth.org/conditions/autism/, accessed 1 February 2024.
[3] World Health Organisation (WHO), ICD-11 for Mortality and Morbidity Statistics: 6B00 Generalised anxiety disorder, Version: 01/2023. Accessed 26 January 2024.

to experience mental illness than non-autistic people. One of the most common of these is Generalised Anxiety Disorder (GAD).

GAD is a common anxiety condition in which people experience persistent, excessive worry about many different things in their lives, as opposed to being triggered by specific situations.[4] Most people experience some symptoms of anxiety in response to stress or danger. However, anxiety becomes a problem when it is regular or excessive and difficult to control, as it can interfere with someone's everyday life, and may also manifest as physical symptoms and as dysfunctional behaviours intended to reduce anxiety.

WHO definition of Generalised Anxiety Disorder

"Generalised anxiety disorder is characterised by marked symptoms of anxiety that persist for at least several months, for more days than not, manifested by either general apprehension (i.e. 'free-floating anxiety') or excessive worry focused on multiple everyday events, most often concerning family, health, finances, and school or work, together with additional symptoms such as muscular tension or motor restlessness, sympathetic autonomic over-activity, subjective experience of nervousness, difficulty maintaining concentration, irritability, or sleep disturbance.

"The symptoms result in significant distress or significant impairment in personal, family, social, educational, occupational, or other important areas of functioning...."[5]

- World Health Organisation,
International Classification of Diseases 11th Revision

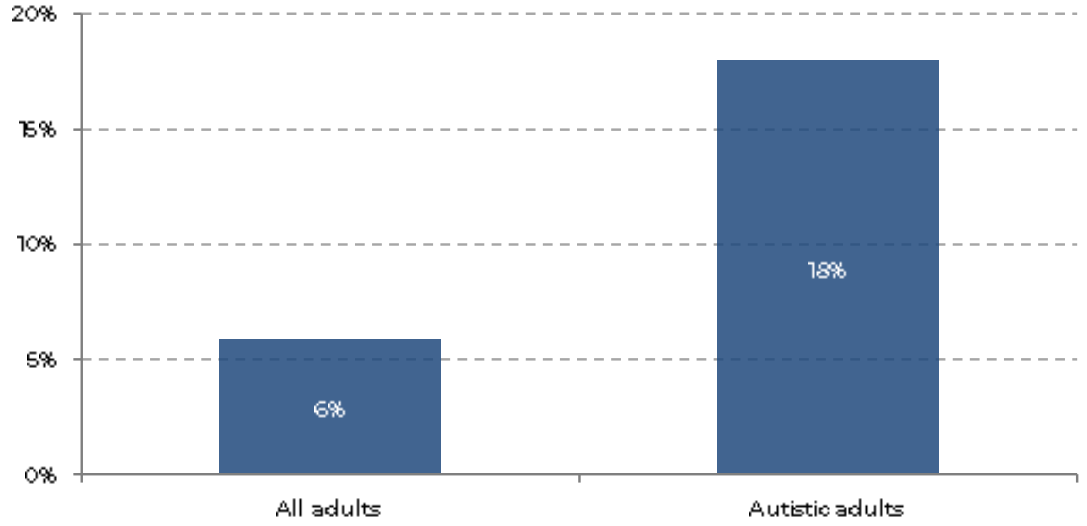
The prevalence of GAD among autistic people is estimated to be very high, with almost 1 in 5 autistic adults in the UK experiencing the condition (or

[4] NHS, Overview - Generalised anxiety disorder in adults,, last modified 5 October 2022. Accessed 10 October 2023.
[5] WHO, ICD-11 for Mortality and Morbidity Statistics: 6B00 Generalised anxiety disorder, Version: 01/2023. Accessed 24 October 2023.

18%).[6] This is around three times the prevalence of GAD in the general population.[7]

Figure 1. Autistic adults are estimated to be three times more likely to experience GAD

Percentage of population with GAD, UK



Sources: M Hollocks et al. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis, Psychological Medicine 49, no. 4: 559-72, 2019. NHS Digital, Adult Psychiatric Morbidity Survey 2014., September 2016.

Treatment for anxiety is not always available or tailored for autistic people

Despite these concerningly high rates of mental illness, autistic people often do not receive appropriate mental health treatment or care. There are many reasons this might be the case, and they stem from both the particularities of ASD and the challenges inherent in researching this area.

First, accessing appropriate care can be challenging for autistic adults. Many barriers exist, ranging from difficulties individuals have in deciding whether to seek help to difficulty communicating with doctors and other staff.[8] Even once with a practitioner, manifestations of anxiety in an autistic

[6] M Hollocks et al. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis, Psychological Medicine 49, no. 4: 559-72, 2019.
[7] NHS Digital, Adult Psychiatric Morbidity Survey 2014., September 2016. Estimated at 5.9% in Table 2.3. The estimate for the prevalence of GAD among the general population is taken from 2014 data covering England only. Again, taking this as proxy for the current prevalence across the UK as a whole is a limitation of the study, and a reflection of the lack of more recent, UK-wide data.
[8] M Doherty et al. Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study, BMJ Open 12, 2, 2002

person can be misattributed to their autism (this is known as 'diagnostic overshadowing'),[9] meaning that they might miss out on the extra support that would be available to anyone diagnosed with anxiety.

Secondly, only recently have institutional and academic work had to account for this combination of conditions. The Diagnostic and Statistical Manual of Mental Disorders, the standard diagnostic manual for mental health illnesses, previously precluded the possibility that autistic people could have anxiety,[10] which has had a major impact on both research and practice.

In addition, standard anxiety treatments may not meet the needs of autistic people. Standard interventions such as cognitive behavioural therapy (CBT) are often language- or emotion-based. Talking and mindfulness therapies, for example, use these. Yet around half of autistic adults are thought to have difficulties in recognising and expressing their own emotions and in distinguishing between them.[11] As noted earlier, communication difficulties are common amongst autistic people, meaning that such interventions would present a particular challenge in their own right. NICE guidelines recommend seeking specialist advice on the modification of such interventions when being used for autistic people – an adjustment which may not always be available.[12]

This is further complicated by the other treatments autistic people might be receiving. For example, the higher likelihood of an autistic person being on medication makes diagnosis and treatment of mental illness particularly complex.

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[9] S Helverschou & H Martinsen (2011), Anxiety in people diagnosed with autism and intellectual disability: Recognition and phenomenology, Research in Autism Spectrum Disorders 5 (1): 377-387, January-March 2011.

[10] "...generalized anxiety disorder is precluded by DSM-IV if ASD is present...", E Gjevik et al. Kiddie-SADS reveals high rates of DSM-IV disorders in children and adolescents with autism spectrum disorders, Journal of Autism and Developmental Disorders 41(6): 761-9, 2010.

[11] E Kinnaird, C Stewart & K Tchanturia, Investigating alexithymia in autism: A systematic review and meta-analysis, European Psychiatry 55: 80-89, 2019.

[12] The National Institute for Health and Care Excellence (NICE), Autism spectrum disorder in adults: diagnosis and management - Clinical guideline [CG142], published: 27 June 2012, last updated: 14 June 2021, accessed 1 February 2024.

New methods of helping autistic people with their anxiety are being developed

Given these challenges, more work is clearly needed to help autistic people access and treat mental health conditions such as anxiety.

MQ Mental Health Research (MQ) is a global charity that supports research to improve prevention, detection and treatments for mental health conditions, as well as working to improve capacities and infrastructure to support the mental health research community. MQ supports researchers who are making strides in improving scientific understanding of mental health issues and developing new ways of preventing and treating them.

The 'Aligning Dimensions of Interoceptive Experience' (ADIE) treatment is one such example. Trialled with the support of MQ, it showed that a training programme more aligned with the needs of autistic people could effectively reduce anxiety in individuals experiencing GAD.[13] The success of the trial may be due to the ADIE treatment better catering to the specific needs of autistic people than more common interventions.

Aligning Dimensions of Interoceptive Experience (ADIE)

ADIE is a treatment which addresses the mismatch between emotional and physiological states in autistic people experiencing anxiety. Imprecise awareness of internal bodily signals (such as a raised heart rate) which signal emotional states may actually make a person more anxious. Anxiety in autistic adults is strongly predicted by a combination of high sensitivity to and low accuracy in awareness of their own bodily sensations.

In clinical trials, participants practised and were given feedback on their performance recognising feelings of anxiety. More participants who received ADIE training showed an improvement in standard measures of anxiety than the active control group: in particular, more recovered from anxiety and more experienced a

[13] L Quadt, et al. Interoceptive training to target anxiety in autistic adults (ADIE): A single-center, superiority randomized controlled trial, *EClinicalMedicine* 39, 101042, 2021.

lowering in their measured level of anxiety. This effect was evident in follow-ups up to a year after the training.

A strength of the programme is that it focuses on interoceptive experience, which may be more effective for autistic people than more common interventions.

Scope of this report

This report focuses on quantifying the potential economic benefits which might arise from making ADIE treatment available to the broader population of autistic adults. The scope does not include a full cost-benefit analysis and is limited to estimating the number of people potentially treated, and the likely improvement in their quality of life as they recover from anxiety.

As costs are a key factor in the economic viability or otherwise of such a treatment, excluding them is naturally a limitation to this analysis. However, the costs of any rollout of the treatment, which might take on a different form to that trialled, do not seem likely to substantially reduce the overall benefits of the treatment. Discussions with the researchers involved suggest that scaling up the treatment would not involve substantial per-participant costs which might make the treatment uneconomic at scale.

The same principles underlying ADIE have since been trialled in a number of different formats, and on other groups of people, with success. Notably, the treatment is being trialled in ways which make it more accessible, such as being able to administer it without supervision by a clinician.

This report does not estimate the potential benefits of the newer forms of ADIE treatment, nor of offering ADIE to a broader group than just people who are autistic. This is because the evidence for ADIE interventions in these circumstances have not yet been published in an academic, peer-reviewed outlet, a process which can take some years. Nonetheless, if similar interventions are indeed effective for non-autistic people and the intervention itself could be rolled out to a wider group, the benefits estimated in this report will underestimate the true impact of the treatment, while still not accounting for the costs of it.

Background

The role of economic analysis

Even once treatments have been found effective in a trial setting, it is important to understand which have the most potential to make an impact outside such settings. Estimating the potential aggregate benefits of a new treatment is an important guide to decisions in public health, research funding and medical practice.

MQ has asked PBE to analyse the ADIE trial, one of its most promising supported anxiety studies which has already gone through the trial phase. Through this analysis, PBE could demonstrate what the scale of the potential benefits of the ADIE treatment might be if it were made available to the whole UK population of autistic people.

Understanding Quality-Adjusted Life Years (QALYs)

While many economic evaluations include benefits such as reduced reliance on health care services or better employment outcomes, the success of the ADIE treatment was measured in terms of the participants' experience of anxiety. In this report two key quantifications of this success are considered: the effect of the alleviation from anxiety in terms of quality-adjusted life years (QALYs), used by NICE to represent the health benefits in terms of improvement in quality of life from an intervention, and its monetary equivalent.[14]

With one QALY representing one year of life in perfect physical and mental health, a condition which detracts from quality of life can be represented as a subtraction from one. It follows that the further from one, the poorer a person's quality of life. For example, a mild anxiety disorder is represented as having a much smaller effect on quality of life than a severe anxiety disorder. The WHO provides QALY-equivalent measures for a range of broadly-defined physical and mental illnesses, including for mild, moderate, and severe anxiety disorders.[15]

[14] Treasury standards value one QALY at £70,000 in 2020/21 prices; this value has been uprated to 2022/23 prices using the GDP deflator.
[15] WHO, WHO methods and data sources for global burden of disease estimates 2000-2019, *Global Health Estimates Technical Paper* WHO/ DDI/DNA/GHE/2020.3: Annex Table C, 2020.

The WHO health weights provide a representative measure of the impact on quality of life of a condition and enable comparisons across a range of conditions. As an illustration, the impact of a mild anxiety disorder on the quality of life of a person, as measured by (reduction in) QALYs, is comparable to that from a mild motor and cognitive impairment. Similarly, the impact of a moderate anxiety disorder is comparable to that of uncontrolled asthma; and for severe anxiety, the terminal phase of cancer (with medication).

In this report a range of estimates of the benefits of the ADIE intervention are presented. This reflects the fact that guidance on use of the health weights has changed recently from recommending that each condition be considered in isolation to recommending that, where multiple conditions are present, the health weights should be combined. The combination is meant to reflect the fact that, for some people, the experience of one condition attenuates the other: for example, even after having recovered from anxiety an autistic person may still exhibit repetitive and/or dysfunctional behaviour or difficulties with social interaction (expressions of both conditions) because of their autism. Others, of course, will not, which would imply their conditions are best considered independently. The most recent guidance from the WHO suggests that being autistic should temper the health weight associated with anxiety (and other conditions). The judgement taken in this report is that both considering conditions separately or together can have merit, and that PBE can at best be agnostic about the preferred method taken when relating to autistic people experiencing from anxiety.

Both GAD and ASD are experienced in different ways. For the purposes of translating the research into wider measures of benefits it is necessary to discuss anxiety as though it were an 'on/off' or easily quantifiable experience, with clear thresholds distinguishing the severity of experiences, when in fact each person's experience is rarely so easy to categorise. While this necessarily imperfect exercise in quantification cannot capture the diversity of experiences of GAD with ASD, it can be a powerful demonstration of the potential representative impact that a treatment like ADIE could have on their lives.

PBE's approach

PBE's approach has been to flesh out a hypothetical scenario in which ADIE treatment is made available to any autistic adult with anxiety, although other restrictions applied in the ADIE trial would not be able to be replicated, as discussed in Annex A.

The calculations follow a four-step process:

1. **Quantifying the potentially affected population**: data from the NHS and ONS as well as academic research are used to assess the number of autistic people in the UK with GAD who seek some form of treatment.
2. **Identifying the potential increase in recovery rates**: by comparing the recovery rates of those who receive and do not receive the treatment in the trial, PBE estimates the increase in the rate of recovery from anxiety that might be expected if the treatment were made available to all autistic people who seek treatment.[16]
3. **Measuring the recoveries in QALYs**: international standards from the WHO are used to quantify the improvement in quality of life (measured in QALYs) that someone who experiences anxiety might experience from alleviation of their condition.
4. **Converting the QALY improvement into economic benefits**: Treasury valuation standards are used to convert this potential improvement into an economic benefit as valued in today's pounds. This would represent the notional value of the improved quality of life experienced by autistic individuals due to reliable recovery from GAD.

Key limitations of economic analysis

In quantifying this hypothetical scenario there are various points at which the limit of what can be known or shown with data are reached. The

[16] The measure of the effectiveness of the ADIE treatment is taken from the difference in the rate of reliable recovery from anxiety between the control and treatment groups. All participants responded to the STAI Trait Anxiety assessment in three post-treatment follow-ups: to be considered as having 'reliably' recovered, trial participants' measured anxiety had not only to pass below the standard clinical threshold for anxiety but also to decrease by a substantial amount. In this report, recovery rates should be interpreted as rates of reliable recovery.

choices or assumptions made at such points could critically affect the resulting estimates of the potential benefits of this treatment. The most important choices which have been made are:

- To assume that three different measures of severity of anxiety are comparable: STAI Trait anxiety, CIS-R, and the WHO health weights.[17]
- To assume that the severity of anxiety amongst autistic people is the same as that across the general population.
- To assume that the effect the treatment had on people who participated in the ADIE trial would be replicated on those who did not.[18]
- To assume that the same share of autistic people who experience anxiety would seek ADIE treatment as the share of the general population who currently seek other available treatments for GAD.

The sensitivity tests explored below show that making different choices could lead to very different overall estimates. Further assumptions which could not be directly tested are also discussed in Annex A. Given the importance of these assumptions, it is worth emphasising that these estimates should be treated as indicative of the broad scale of potential benefits rather than as precise measures.

As noted earlier, another key limitation of the analysis is that the potential costs of a roll-out are not considered, and thus this study does not constitute evidence on value for money.

[17] It should be noted that an early study of the CIS-R measure, which underlies statistics on the severity of anxiety in the population, showed that it compared quite poorly with the international definitions underlying the WHO health weights. (T Brugha et al. Cross Validation of a General Population Survey Diagnostic Interview: a Comparison of CIS-R with SCAN ICD-10 Diagnostic Categories, Psychological Medicine 29, no. 5: 1029–42, 1999.)

[18] This includes not only people who would have been eligible but did not participate, but also people excluded by restrictions placed on participants, which would not be replicable in a real-world roll-out.

Results of the analysis

Making ADIE available to all autistic people experiencing anxiety in the UK who seek treatment might lead to 53,000 people accessing ADIE treatment.[19] Almost 6,000 more people might make a recovery from anxiety than would without ADIE treatment being available.

The improvement in quality of life experienced by all the people making a recovery from GAD is equivalent to between 1,700-2,300 QALYs. Expressed in economic value, the benefits of this treatment could be between £125-£170 million, equivalent to £21,000-£28,000 per treated person who recovers.

As noted earlier, there is a case for presenting estimates that both do and do not take into account any interaction between anxiety and autism in a person's quality of life. The upper limits of the ranges of the estimates represent scenarios in which the improvement in quality of life experienced by an autistic person who recovers from anxiety is quantified as having no overlap with autism. The lower limits represent recovery from anxiety being attenuated by some residual symptoms which are common to both anxiety and autism. The attenuation reduces the estimated benefits by around 25%.

Impact of ADIE

"...I think [the task] is definitely a helpful tool. I have actually found it much more calming [to try] to listen to my heartbeat."

- Tom, a study participant

Strikingly, these benefits are thought to be persistent. In the trial, the reliable recovery rates remained constant throughout the follow-ups in the year afterwards. This is particularly remarkable as recovered people of conditions like anxiety are typically prone to relapse within that time period

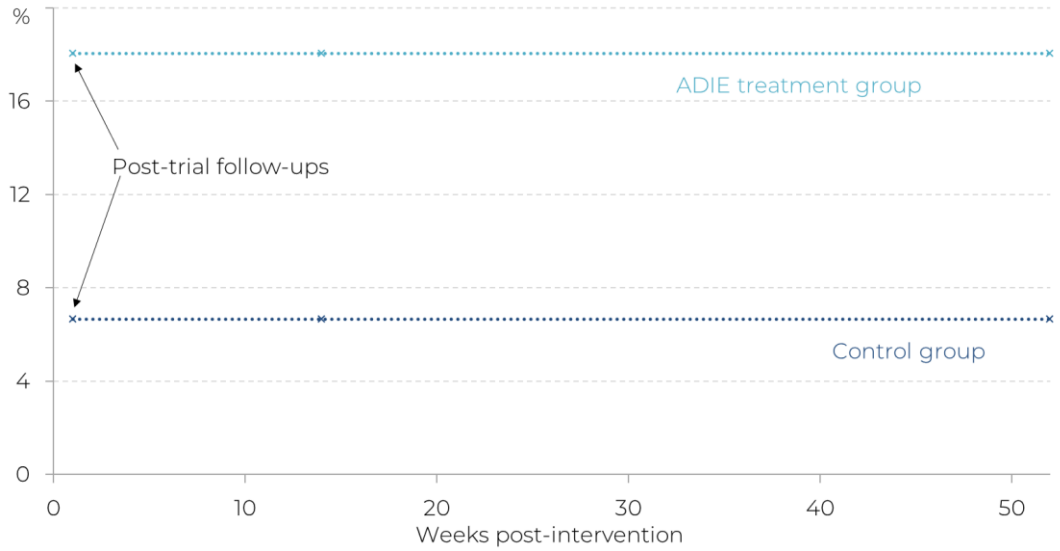
[19] A full summary of quantitative estimates is given in Annex B.

following treatment, so a reduction in recovery rates over time would typically be expected.[20]

The estimated benefits above should be interpreted as reflecting the likely benefit over an initial year after treatment only, however, as data does not exist beyond this point.

Figure 2. Recovery rates were remarkably stable at all post-treatment follow-ups

Recovery rates in control and treatment groups



Notes: Follow-ups were held one week, three months, and one year after the trial.
Source: L Quadt, S Garfinkel, J Mulcahy, D Larsson, M Silva, A Jones, C Strauss, & H Critchley. (2021): "Interoceptive training to target anxiety in autistic adults (ADIE): A single-center, superiority randomized controlled trial," EClinicalMedicine 39, 101042; L Quadt, email to author, 22 January 2024.

[20] S Ali et al. How durable is the effect of low intensity CBT for depression and anxiety? Remission and relapse in a longitudinal cohort study, Behaviour Research and Therapy 94, July: 1-8, 2017.

Sensitivity analysis

The estimates above are sensitive to the choices outlined earlier in this report. This is demonstrated below with some sensitivity tests, which explore how the estimates change under a range of different assumptions:

- Sensitivity Test 1 – variations in the treated group
- Sensitivity Test 2 – anxiety in the population of autistic people

Sensitivity Test 1 – variations in the treated group

The sources of information on GAD and ASD are thin. Baseline estimates of the following have been chosen from reputable sources which generally represent central estimates:

- Share of UK adults who are autistic
- Share of autistic adults who have GAD
- Share of people with GAD who seek treatment.

Each of these figures could be different in reality. Various other sources present credible alternatives for the first two figures. In the case of the third, while it seems unlikely that the share of autistic people who seek treatment for GAD would be the same as the share who seek treatment in the general population, given the typical difficulties outlined earlier in this report, no information on that specific number has come to light.

Any variation in the shares above would flow through to have an equally large (in percentage terms) effect on the number of people treated, and thus on the magnitude of estimates presented. This is true whether the variation is higher or lower – that is to say, if autistic people are half as likely to seek treatment for anxiety than the general population, the baseline estimates would be halved.

An example can illustrate this: in this sensitivity test it is assumed that the share of autistic adults who have GAD is not 18%, but 40%, in line with a recent survey.[21] This is a 122% increase. Under such a scenario, the benefits estimated would range between £280-£375 million. These estimates are 122% higher than the baseline range.

[21] Good practice guide for professionals delivering talking therapies for autistic adults and children, National Autistic Society, accessed 29 January 2024.

Sensitivity Test 2 – anxiety in the population of autistic people

The effects of anxiety may range from mildly disruptive for some to incapacitating for others. WHO measures representing the effect of three broad levels of anxiety disorder (mild/moderate/severe) on quality of life are used to translate the impact of recovery from anxiety into QALYs. NHS data has been used to quantify the share of mild, moderate, and severe anxiety in the population. Again, though, these are shares reflecting anxiety in the general population, whereas levels of anxiety amongst autistic people may differ.

To give a sense of how sensitive estimates are to assumptions made about the level of anxiety in autistic people, this sensitivity test shows how the estimated benefits vary under alternative assumptions: that autistic people in general who would seek this treatment are all experiencing either mild, moderate, or severe anxiety. Each assumption is clearly unrealistic; the purpose of the exercise is to understand how heavily the estimated benefits rely on the choices made.

In a scenario in which all autistic people with anxiety experience only mild anxiety, the estimated aggregate benefit of ADIE treatment amounts to just £10-£13 million, 92% less than the baseline estimate. On the other hand, if all autistic people with anxiety were assumed to experience severe anxiety, the estimated benefits are 37% higher at £180-£230 million. The lop-sided nature of these scenarios reflects two key facts: the bulk of people in the general population identified as having anxiety experience relatively severe symptoms; and the estimated improvement in quality of life resulting from a recovery from mild anxiety is much smaller than that from moderate or severe anxiety.

Conclusions of sensitivity analysis

The modelling choices made have a large impact on the potential benefits estimated. However, under all scenarios tested, the ADIE treatment could be expected to generate substantial benefits if it were made more broadly available.

The estimates are sensitive to assumptions about the number of people who would be treated, but this flows through proportionately only to total economic benefit as the per person economic benefits remain the same.

More complexity comes from assumptions about the severity of anxiety amongst autistic people. The limits of what is known about the combination of autism and anxiety places severe restrictions on what can be said with any certainty in this report, hence the wide bounds presented.

Recommendations for researchers and funders

Effective treatments like ADIE are advancing the frontier of treatments for anxiety. The collaboration between the researchers, MQ Mental Health Research, and PBE in analysing the potential impact of this treatment is a great step in the right direction, and a valuable contribution to mental health research sphere.

Recommendations for researchers

The procedure followed in this report is typical of an economic benefit analysis; however, as demonstrated, when confronted with real-world data constraints the precision of the estimates is heavily restricted. Researchers can improve the prospects of precise benefits being made of new treatments by:

- Evaluating their treatment in a Randomised Control Trial setting (if not in initial stages then planning to do so in later trials);
- Running trials with large sample sizes, to enable more granular analysis;
- Running long-term evaluations of trials;
- Specifying the appropriate population for a new treatment;
- Documenting the costs of their interventions, and making estimates of how costs might change outside a trial setting.

Recommendations for research funders and donors

Outside the context of trialling new treatments, a major constraint on the precision of the estimates in this report is the lack of detailed, recent data on mental health in autistic people: there is a paucity of information available and, as the literature is not well developed, a wide range of estimates of key figures exist. Better data, and thus more research, is needed to improve any future attempts to quantify the potential benefits of new treatments.

MQ works closely with researchers and encourages them to rigorously evaluate their interventions in accordance with scientific standards. It, and other organisations which direct funds to mental health research, can also

be important levers in facilitating such improvements. Research funders and donors could support more research into:

- The prevalence of mental health illnesses in autistic people, particularly in terms of severity and co-morbidities;
- The specific challenges autistic people face in seeking treatment for mental illness;
- Variations on treatments to more specifically meet the needs of autistic people.

MQ has highlighted the lack of funding for mental health research in the past. The sector might benefit from attention being drawn to the challenges autistic people face in managing their mental health.

Better understanding of the interaction between mental health issues and the specific needs of autistic people is necessary and important in itself. But broader research on mental health issues cannot be fully representative if it excludes any neuro-diverse populations. Mental health research funders and donors can also encourage and support patient and public involvement in research, to facilitate the participation of neuro-diverse populations and/or their carers in research. Such developments would make it possible to evaluate potential benefits of any interventions with more accuracy, to the benefit of society at large.

Conclusion

The overlap between autism and anxiety is substantial, poorly understood, and a difficult area to manage in terms of treatment. ADIE treatment, being more specifically tailored to the needs of autistic people than standard interventions, has the potential to significantly improvement the welfare of the large share of autistic people who experience anxiety.

The ADIE training was shown to be effective in helping participants recover from anxiety in clinical trials. PBE's estimates suggest that if this treatment were rolled out to autistic people in the general population, 53,000 people might be both eligible and likely to seek treatment for their anxiety, and an additional 6,000 people might be expected to experience at least a temporary recovery from anxiety.

The improved quality of life which might result would also be substantial: central estimates suggest in aggregate these could be measured as between 1,700-2,300 additional quality-adjusted life years, which is valued at £125-£170 million. The range of estimates reflects doubt about whether the calculation of the improvement in quality of life as a result of recovery from anxiety should be attenuated by a person's autism. Nevertheless, the positive benefits are thought to be substantial.

Annex A – Detailed Methodology

The structure of this Annex follows the four-step approach to calculations outlined in the main body of the report.

Quantifying the potentially affected population

The size of the total UK population aged 18 and over comes from ONS estimates – the most recent available are for mid-2021.[22] Figures relating to autism vary across studies, but those used are relatively central or conservative estimates from NICE (stating 1.1% of adults have ASD) and a literature review by Hollocks et al (18% of ASD adults have GAD).[23] Figures from the NHS 2014 Adult Psychiatric Morbidity Survey were used for the share of adults with GAD receiving any treatment (49.9%).[24] The potentially affected population is calculated as:

$$\begin{aligned} &\textit{Adults who might seek treatment} \\ &\quad = \textit{UK population } (\textit{aged } 18+) \\ &\quad \times \textit{Prevalence of Autism Spectrum Disorder} \\ &\quad \times \textit{Share of those with ASD who have GAD} \\ &\quad \times \textit{Share of those with GAD who have sought treatment} \end{aligned}$$

The overall estimated benefits vary with the estimated number of adults who might seek treatment; it follows that if any of these component figures are underestimated so too will be the estimated potential benefits. As outlined in sensitivity tests, an increase in the number of people who would potentially undertake ADIE training would naturally increase the aggregate estimated benefits. Given the paucity of research on mental health conditions amongst autistic people, some of the sources used at best approximate the information needed.

First, a number of estimates of the prevalence of anxiety amongst autistic people exist; however, many capture all anxiety disorders, or misleadingly quote studies focused on children or adolescents. A range of estimates exist for other populations and countries.

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[22] ONS, Estimates of the population for the UK, England, Wales, Scotland and Northern Ireland, Table MYE2, 2022.

[23] NICE, Autism in adults: How common is it?, Version: 05/2020. Accessed 29 January 2024; M Hollocks et al. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis, Psychological Medicine 49, no. 4: 559-72, 2019.

[24] NHS Digital, Adult Psychiatric Morbidity Survey 2014., September 2016. See. Table 3.2 in particular,

It is possible that levels of anxiety in autistic adults may have increased in recent years. The figures used (from an academic study by Hollocks et al) are based on studies published between 2008 and 2016. Sources covering anxiety in the general population in more recent years, such as the ONS wellbeing measures, show that people report that their anxiety is now higher than before the Covid pandemic.[25]

The NHS survey figures on the share of people with GAD who seek treatment only represent England; in using this to represent mental health in the whole of the UK there is an implicit assumption that the likelihood of seeking treatment is not substantially different in Scotland, Wales or Northern Ireland.[26]

Moreover, the NHS survey gives the propensity to seek treatment amongst all adults with GAD; figures representing the propensity amongst autistic adults were not available but, on balance, are likely to be lower. The survey itself found that autistic people were, if anything, less likely to seek treatment for any mental health issues than the general population, despite the higher incidence of mental health conditions.[27] Various studies have shown that autistic adults face barriers in accessing health care ranging from deciding whether symptoms are severe enough to justify a GP visit to difficulty communicating with doctors and their staff.[28]

That said, given that ADIE treatment may be more tailored to the needs of autistic people than present common treatments, more people may be encouraged to seek treatment than currently seek available treatments, which would attenuate such an effect.

[25] ONS, Annual personal well-being estimates, year ending March 2012 to year ending March 2022, Table 10, 2023.
[26] ONS annual person well-being estimates suggest that the profiles of anxiety in England, Scotland, and Wales are quite similar. (ONS, Annual personal well-being estimates, year ending March 2012 to year ending March 2022, Table 10, 2023.)
[27] McManus et al. Table 6.6, 2016.
[28] For example, M Doherty et al. Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study. BMJ Open 12, 2, 2022.

A number of inclusion and exclusion criteria were placed on the participants by the researchers, ranging from age and fluency in English to vision and hearing, brain injury, and experiences of psychosis. It is not possible to replicate such a combination of inclusion and exclusion conditions with aggregate data; instead it is necessary to assume that the people who were excluded from these studies as a result of these criteria are not likely to have very different outcomes to those who participated.

The ADIE researchers indicated that, for the most part, these exclusions were made for the purposes of evaluation rather than because there was some reason to expect these people would have a particularly different response to the treatment, and that if the treatment were made freely available there would not be any reason to preclude such people from treatment.

Identifying the potential increase in recovery rates

The ADIE evaluation was conducted as a Randomised Control Trial, the 'gold-standard' of evaluation. The trial showed that participants who received ADIE training were more likely to make a recovery from anxiety than participants who undertook the control training (which was not expected to be as effective): at three points after completing the training the ADIE group showed better rates of recovery from anxiety than the control group.

Before extrapolating these improvements to population data, it is important to check that these are greater than what might be explained by day-to-day variation in measured anxiety scores. A z-test shows that the treatment group had significantly larger recovery rates than the control group at all three follow-ups at the 10% significance level.

The baseline estimates take the trial results, which are the same in all three evaluations, as the representative improvement in recovery rates. As a result, there is no assumed relapse into anxiety at an aggregate level – a strong assumption, given that anxiety and similar conditions are typically quite prone to relapse.

It is worth noting that the control group in this trial were 'active': they had a similar test and feedback process in order to simulate treatment. However rather than focusing on interoceptive awareness, they were tested on

recognition of emotional reactions in others, a treatment more akin to current therapeutic interventions for anxiety. It is possible the training may still have caused some small improvement in the control group participants' anxiety; if so, the trial outcomes would understate the real effect of ADIE treatment.

Measuring the recoveries in QALYs

The WHO publish health weights which represent a change in quality of life as a result of a comprehensive list of health states, both physical and mental.[29] The weights for autism and for anxiety disorders are given in Table A1.

Table A1. WHO Health state weights indicate severe anxiety substantially diminishes quality of life

Health state	Lost QALY, 2019
Anxiety disorders: Mild	0.03
Anxiety disorders: Moderate	0.133
Anxiety disorders: Severe	0.523
Autism	0.262

Source: WHO, 2020

These health weights can be applied directly to QALYs. QALYS have a maximum value of one and minimum value of zero: for example, having an illness with a health weight of 0.25 for a year is equivalent to reducing the amount of time lived in perfect health by a quarter, or down to nine months out of a year. In the case of anxiety, the improvement in quality of life resulting from a recovery from a severe anxiety condition is worth more than half a QALY (equivalent to increasing the amount of time lived in perfect health by more than half a year), while that from a mild anxiety condition is estimated as being worth just 0.03 QALYs.

The health weights also offer a weight for autism. Invocation of this weight in this report does not necessarily imply that a healthy autistic person's quality of life is automatically less than that of a healthy non-autistic person; the measures of benefits in this report simply reflect improvements

[29] World Health Organisation, 2020.

in quality of life experienced by a person going from a state in which they experience an anxiety disorder to a state in which they do not.

Nonetheless the lower limits of the estimated ranges of benefits reflect the interaction between anxiety and autism in a person's quality of life. This reflects the most recent WHO guidance, which indicates that, to account for comorbidities, the weights reflecting the loss of quality of life from anxiety should be combined with weights reflecting the loss of quality of life associated with autism. This results in a recovery from anxiety by an autistic person having a slightly lower weight than recovery by someone whose anxiety does not overlap with their autism, reflecting the fact that, for example, an autistic person who recovers from anxiety may still retain some symptoms which are common to both anxiety and autism (such as restlessness or repetitive or compulsive behaviour). As stated in the main body of the report, by presenting a range of estimates PBE wishes to reflect the fact that, while it is WHO guidance to assume these overlap, there is merit to considering the possibility these experiences will be independent in some individuals.

Figures from the NHS 2014 Adult Psychiatric Morbidity Survey were used to give the share of adults with mild, moderate, and severe anxiety (Table 1).[30] Again, the NHS survey was only carried out in England, and only represents anxiety in the general population. To use these figures to represent anxiety across the UK is to assume that the severity of GAD is not substantially different in Scotland, Wales or Northern Ireland, and to use them to represent anxiety in autistic people is to assume the severity of GAD is not substantially different amongst autistic people than it is in the general population. It should be noted that the measure of severity used in the data are based on the Clinical Interview Schedule-Revised (CIS-R) measure which is written to cover a range of mental health disorders and may differ from the STAI Trait measure.

The ADIE trial used the standard STAI Trait measure, which scores anxiety on a range from 0 to 80, and categorises severity into mild (20-39), moderate (40-59), and severe (60-80) anxiety. In the ADIE trial a person was considered recovered from anxiety if their anxiety decreased by at least 6 points on the scale and crossed the 'caseness' threshold of 55. A person

[30] McManus et al. Table 2.5, 2016.

may, therefore, be considered clinically 'recovered' while still experiencing mild or moderate anxiety. Throughout this report this recovery is nonetheless treated as a full recovery (i.e. returning to a health weight of one, less the weight placed on autism in the relevant scenarios) as the sample size of ADIE trial participants is too small to precisely model improvement to mild and moderate anxiety separately to recovery to minimal (essentially, zero) anxiety. The overall impact of this decision on the central estimates is minimal.

The total improvement (in QALYs) due to recovery after the ADIE treatment is calculated as:

$$\begin{aligned} QALYs\ gained = {} & Adults\ who\ might\ seek\ treatment \\ & \times Improved\ recovery\ rate\ due\ to\ ADIE \\ & \times (health\ weight\ for\ mild\ anxiety \times \%\ mild \\ & + health\ weight\ for\ moderate\ anxiety \times \%\ moderate \\ & + health\ weight\ for\ severe\ anxiety \times \%\ severe) \\ & \times Scaling\ for\ gradual\ relapse \end{aligned}$$

As noted in the main body of the report, the high weight on recovery from severe anxiety means that, as quantified in this report, the value of a recovery from severe anxiety is substantially more beneficial than a recovery from mild or moderate anxiety. Table A2 gives indicative economic values for people with varying levels of anxiety, showing the range of estimates accounting for the two methodological approaches to account for the impact of autism.

Table A2. The representative benefit of treatment per person is very high for those experiencing severe anxiety

Initial level of anxiety	Value of improved quality of life from recovery	Value of improved quality of life from recovery, accounting for overlap with autism
Mild	£2,222	£1,640
Moderate	£9,851	£7,270
Severe	£38,738	£28,589

Sources: PBE analysis of WHO, 2020; Quadt et al, 2021; HM Treasury, 2022; HM Treasury, 2023

Converting the QALY improvement into economic benefits

The Treasury 'Green Book' provides a standard valuation of £70,000 in 2020/21 prices for one QALY.[31] This valuation is uprated to reflect 2022/23 prices using the GDP deflator, also published by Treasury – an increase of approximately 6%.[32] Each monetary estimate is calculated as:

$$£\ gained = QALYs\ gained \times 70000 \times 1.058$$

[31] HM Treasury, The Green Book, last modified 18 November 2022. Accessed 28 September 2023.
[32] HM Treasury, GDP deflators at market prices, and money GDP June 2023, last modified 2 October 2023. Accessed 10 October 2023.

Annex B – Full quantitative results

Table B1. Potential benefits of rolling out the ADIE treatment under various scenarios

	Number of people who might be treated	Number of extra people who might recover	Improvement in QALYs	Equivalent economic value	Change vs central estimate
Central estimate	52,588	5,977	1,689-2,289	£125-170 million	--
Sensitivity Test 1 – variations in treated group					
Higher GAD prevalence	116,863	13,283	3,753-5,086	£278-377 million	+122%
Sensitivity Test 2 – anxiety in the population of autistic people					
All mild	*	*	132-179	£10-13 million	-92%
All moderate	*	*	587-795	£43-59 million	-65%
All severe	*	*	2,307-3,126	£171-232 million	+37%

Notes: *indicates no change from central estimates
Sources: PBE analysis of ONS, 2022; WHO, 2020; McManus et al. 2016; Quadt et al. 2021; HM Treasury, 2022; HM Treasury, 2023

Annex C – Glossary

Assumptions
A statement accepted as true without proof. In this report assumptions represent choices made to fill in gaps in what can be known based on current data.

Autism Spectrum Disorder
A neurodevelopmental disability characterised to different extents in different individuals by challenges related to social communication and interaction, by repetitive, restrictive, and inflexible behaviour, by highly-focused interests, and by hyper- or hyposensitivity to sensory stimuli.

Control Group
A group of experiment participants to whom treatment is not administered; comparing their outcomes before and after the experiment helps account for outcomes that individuals would experience in the absence of treatment.

Economic Value
A measure of a concept put in monetary terms. In this report standard Treasury valuations of QALYs are used to give an equivalent economic value to the quality of life someone might experience from recovering from anxiety. One way to conceptualise this is to imagine this as the amount a person would be prepared to pay to experience the same improvement in their quality of life.

Generalised Anxiety Disorder (GAD)
A common anxiety condition, in which people experience persistent, excessive worry about many different things in their lives. Some measures of the intensity of symptoms of GAD categorise people's experience into mild, moderate, and severe.

Quality-adjusted life year (QALY)
A measure of a person's wellbeing or quality of life. One QALY represents one year of life lived in perfect physical and mental health.

Randomised Control Trial
A form of experiment in which participants are randomly assigned to either

a control or treatment group, and the true effectiveness of the treatment is understood by comparing outcomes for both groups.

Recovery

No longer having symptoms of anxiety serious enough to be regarded as clinical (moderate or severe anxiety). This report follows current NHS standards, which requires a person's STAI Trait Anxiety score to not only decrease from 55 or more to below that (a standard clinical threshold), but also to change by at least 6 between the baseline and follow-up measures of anxiety (often referred to as 'reliable recovery').

Relapse

Returning to a clinical level of anxiety, after having previously been measured as having made a reliable recovery. Relapse is a typical characteristic of many common mental health disorders which may prove difficult to recover from in the long term. Treatments may vary in how persistent they are; that is, how long after a given treatment an individual remains recovered from anxiety before relapsing.

Sensitivity test

Where assumptions must be used to fill gaps in what can be known, a sensitivity test can demonstrate how sensitive the results of an economic analysis are by varying the choices made.

Treatment Group

A group of experiment participants to whom treatment is administered; comparing their outcomes before and after experiment in isolation provides suggestive, but not conclusive, evidence about the effectiveness of the treatment.

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www.probonoeconomics.com

020 3632 2668