Eating disorders and autism: extension of the PEACE pathway to children and young people

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Abstract

A greater susceptibility to development of eating disorders (EDs) has been recognised among people with autism since the 1980s. Standard treatment approaches for EDs can be less effective for those with autism or autistic features, but there are no separate guidelines for the management of EDs in this population. The clinical need for autism to be understood and accommodated better in ED services has become increasingly apparent in recent years. The PEACE (Pathway for Eating disorders and Autism developed from Clinical Experience) pathway, was launched by the London Maudsley Hospital in 2017 and is the first treatment approach to be developed specifically for autistic adults receiving inpatient treatment for an eating disorder. Following the success of the PEACE pathway in London, three years of innovation funding was granted to child and adolescent ED services in Buckinghamshire, Oxfordshire and Berkshire (BOB) to support the local implementation of this approach in community services. The aim was to apply similar principles while offering reasonable adjustments and ensuring the delivery of neuroinclusive care. Initial evidence suggests that the proactive, neuro-affirming approach to ED treatment in young people with autism emphasised by PEACE can improve treatment experience, reduce risk and shorten or avoid higher-intensity treatments for some patients. It is hoped that the care delivery model, adaptations and resources developed as part of the BOB PEACE implementation will be adopted more widely to benefit many more autistic children, young people, adults and families struggling with EDs.

Keywords: autism, anorexia nervosa, bulimia nervosa, binge eating disorder, ARFID, pica, eating disorder services, PEACE pathway

1. Introduction

Autism is a neurodevelopmental condition in which persistent deficits in social communication and social interaction, and behavioural patterns characterised by restrictive or repetitive interests or activities, emerge in early childhood (1). Although the features of autism must be present during the early developmental period, functional impairment may not be apparent immediately and may only emerge when social demands exceed ability (1). Estimates based on the updated diagnostic criteria for autism suggest that global prevalence in the general population is approximately 1% to 3% (2, 3). Autism is disproportionately diagnosed in males, with a male:female ratio of between 3:1 and 4:1 (3, 4).

This article is divided into two parts. In the first part, we provide an overview of current research on autism in eating disorders (EDs) and discuss the implications for treatment of EDs in people who also have autism. In the second part, the development and implementation of a specialised treatment approach for people with coexisting autism and anorexia nervosa (AN), bulimia nervosa (BN) or binge eating disorder (BED), the Pathway for Eating disorders and Autism developed from Clinical Experience (PEACE), is described in detail.

2. Review of autism in individuals with eating disorders

2.1 Background

An association between autism and ED susceptibility was first proposed in 1983 by Christopher L. Gillberg (5), who later suggested that infants who showed low empathy during early development were predisposed to EDs in later life (6). Decades later, the results of an analysis of data from the Avon Longitudinal Study of Parents and Children (ALSPAC) (7) found that adolescents who developed disordered eating patterns at age 14 years had overall higher Social and Communication Disorders Checklist (SCDC) scores, and a 20% increase in SCDC scores from the age of 7 years, compared to those who did not develop disordered eating. The authors concluded that autistic social deficits in childhood may increase the risk of disordered eating in adolescence. Since Gillberg's original observations, numerous studies have described various autism-like features in individuals with EDs, including weak central coherence and cognitive inflexibility (8-10), obsessive-compulsive features (11, 12) and broad social difficulties (13-15), as well as similar theory of mind deficits in people with autism and those with AN (16). These findings have even led some authors to question whether AN, the ED for which there is most evidence, may be a "female form" of autism (17, 18).

There is now extensive evidence that individuals with EDs are more likely to exhibit autistic features or to meet autism diagnostic thresholds than those without EDs (19), and a growing consensus that coexisting autism is associated with more severe ED presentations, greater chronicity and poorer outcomes (19-23).

A clear determination of the extent of co-occurring autism–ED is still lacking, however, and estimates of the prevalence of autism among people with EDs vary. This partly reflects differences in diagnostic criteria, study methodologies and populations between studies (24). Many studies lack comprehensive assessment of autism, despite growing recognition of the association and the implications for management (19). Diagnosis may also be confounded by the overrepresentation of females among those with EDs, which is in contrast to the preponderance of males diagnosed with autism; it has been suggested that assessment scales may not be as reliable in diagnosing autism in females (25), implying that autism may be more prominent in this group than previously thought.

The picture is further complicated by the findings from studies that suggest observed autistic traits may more accurately be characterised as state-dependent features of the ED, rather than indicative of true autism, which is a pervasive disorder implying that it persists over time (22, 26-28). However, there is good evidence that, in many cases, autistic features are present before the emergence of the ED (22, 25), and persist after recovery (29-32), supporting the conclusion that autism is likely to be a risk factor for disordered eating. The authors of a recent longitudinal study in 24 adolescents with AN (23) concluded that autistic characteristics showed evidence of both trait and state phenomena, observing that underweight and starvation in the acute phase of the ED might have an exacerbatory influence on pre-existing autistic features. These findings were largely consistent with the conclusions of an earlier systematic review (25) that found evidence that at least some autistic features in individuals with AN remain stable over time and are not related to body weight.

Evidence for the association is further strengthened by studies showing familial patterns of coexisting autism and AN (33, 34), suggesting the possibility of a shared genetic susceptibility. An analysis of Danish registry data (34) found that both coexisting autism and a family history of autism are more common in people with AN than in the general population. In this study, data for 5006 individuals with AN and 12,606 individuals with autism were analysed together with data for their parents and full and half siblings. Probands who were first diagnosed with AN had a greater risk of a later autism diagnosis (hazard ratio [HR] = 15.08; 95% CI, 12.23–18.58), and probands who were first diagnosed with autism had a greater risk of a later AN diagnosis (HR = 5.39; 95% CI, 4.37–6.64). AN in a first-degree relative also increased the risk of autism in probands (HR = 1.80; 95% CI, 1.43–2.28), and autism in a first-degree relative increased the risk of AN (HR = 1.45; 95% CI, 1.09–1.94). However, the elevated risk of coexisting autism in AN probands, and of autism diagnosis in relatives of AN probands, did not differ significantly from that for other psychiatric disorders, suggesting that the association may not be specific to autism.

2.2 Prevalence of autism in individuals with eating disorders

Much of the current research on autism and EDs is limited to studies of AN; the association between autism and other EDs has been much less extensively investigated and few data are available on the prevalence of autism and autistic traits in, for example, BN, BED or avoidant/restrictive food intake disorder (ARFID). Estimates of autism prevalence in the general population have changed markedly over recent years, largely as a result of the revised diagnostic criteria as well as increasing awareness. This implies that the recognition of autism in individuals with EDs may also have increased, and correspondingly that autism prevalence figures reported in older studies may underestimate the extent of co-occurring autism–ED.

2.2.1 Anorexia nervosa

Estimates based on self-report using the autism quotient (AQ) suggest that up to 40% of adolescents and 26% of adults with AN meet the diagnostic cutoff for autism (35, 36). Studies using clinician-administered assessments, such as the Autism Diagnostic Observation Schedule (ADOS), have reported similar figures overall, but with some variability in item subscores, suggesting a narrower autistic profile in some individuals. For example, a study in 60 women with severe AN (37) found that 14 (23%) met the clinical cutoff for autism on the revised ADOS (ADOS-2), but while all showed social impairments, only eight (13%) demonstrated repetitive or restrictive behaviours. Another study by the same authors (38) found that out of 40 adolescent females with AN attending inpatient and day-patient ED services, four (10%) met full research criteria for autism, based on ADOS-2 scores and a review of their developmental histories. A further 17 (40%) met the ADOS-2 diagnostic cutoff without fulfilling the developmental criterion. A study in 150 adolescent outpatients with AN or subthreshold AN (14) reported below-average scores on measures of social aptitude and above-average scores on measures of peer relationship problems and obsessive-compulsive symptoms, but only six individuals (4%) were considered to meet diagnostic criteria for "possible" (n = 5) or "definite" (n = 1) autism. Similarly, a study comparing AQ, ADOS and Social Responsiveness Scale scores in 218 young females (aged 12–30 years) with either current or recovered AN (without a previous diagnosis of autism), or autism, and a "typically developing" control group (39), found that, while the AN groups had higher levels of autism features than the control group, they were less likely to show impairments in verbal and non-verbal communication, social interaction and imagination/creativity than the autism group. However, the AN groups were only reliably differentiated from the autism group on

the ADOS-2 "quality of social response" item.

The importance of using appropriate criteria for assessment of autistic features in older adolescents and adults with AN was demonstrated in a study by Sedgewick et al. (40). The authors used a revised version of the ADOS-2, which was specifically developed for use in this population, and compared diagnostic outcomes with those obtained using the original version of the scale in a sample that included 66 women and girls with current AN (AN group), 46 in recovery from AN (REC group), and 63 controls who had never had an ED (HC group). Using the original algorithm, five of the HC group, 13 in the AN group and seven in the REC group scored above the diagnostic cutoff for autism. The revised algorithm resulted in a greater number meeting the diagnostic cutoff in each of the three groups: six in the HC group, 18 in the AN group and nine in the REC group. Notably, the revised ADOS-2 scores were not significantly correlated with ED symptomatology, suggesting they were indicative of underlying autism and not state-dependent features of AN.

In summary, autistic features are common in individuals with AN. The studies summarised above, and recent reviews (24, 25), suggest that 20% to 35% may meet ADOS-2 diagnostic criteria for autism. However, the autistic profile of individuals with AN appears to differ in many cases from that of individuals with autism without AN. This may partly reflect the largely female samples in AN studies but also suggests a distinct autism presentation in AN.

2.2.2 Bulimia nervosa and binge eating disorder

While relatively few data are available for other EDs, study samples that have included individuals with AN, BN and BED have suggested that the numbers meeting diagnostic criteria for autism are similar across ED types. Gesi et al. (41) were the first to identify a higher degree of autistic features in individuals with BN and BED than in healthy controls. A later systematic review of studies investigating autism and ADHD in individuals with AN, BN or BED (42) reported that, overall, 4.7% had a DSM-III, DSM-IV, DSM-5 or ADOS-2 diagnosis of autism, which was the same rate as that for the AN subgroup when analysed separately. Similarly, among 71 ED outpatients attending a specialised ED hospital (43), 28%, 40% and 31% of those with AN, BN and BED, respectively, were classified as having "high level autistic traits" (HAST), according to DSM-5 criteria and clinical assessment. The difference between the rates of HAST in AN and other EDs combined was not statistically significant.

2.2.3 Avoidant/restrictive food intake disorder

Since 2013, when it was first defined as a distinct ED in the DSM-5, several studies have investigated coexisting autism in ARFID. A systematic review of ARFID in children and adolescents (44) reported prevalence estimates of coexisting autism in children with ARFID of between 8.2% and 54.8% across six studies. Between 21% and 28% of children with autism were considered to be at high risk of developing ARFID. The DSM-5 characterises food restriction in ARFID as resulting primarily from heightened sensitivity to the sensory aspects of food (e.g., appearance, colour, smell, texture, temperature or taste), rather than a preoccupation with body weight or shape (1). Similar restrictive eating behaviours and sensory sensitivities are commonly seen in individuals with autism without a diagnosed ED, which may contribute to a particular risk of developing ARFID in this population (45). However, differences in social functioning, sensory processing and eating attitudes have been reported in children with coexisting ARFID-autism, compared to children with autism only (46). Unusually among EDs, ARFID is diagnosed equally in males and females; however, coexisting ARFID-autism is more common in males (1).

2.2.4 Pica

Pica is characterised as persistent (>1 month) consumption of non-nutritive, non-food substances (1). As with ARFID, the impetus for abnormal eating behaviours in pica is not a preoccupation with weight or body image. Analysis of data from the ALSPAC study (47) showed pica behaviours were present in 3% of children at one or more regular follow-up reviews between the ages of 36 months and 115 months (9 years, 7 months). Pica was most commonly reported at 36 months and decreased later in development. At all five follow-ups (at 36, 54, 65, 77 and 115 months), pica was significantly associated with autism ($p < 0.001$). The percentage of children with pica who also had a diagnosis of autism was not reported, however.

2.3 Treatment approaches to eating disorders in individuals with autism

There is a consensus that standard treatment approaches for EDs can be less effective for those who also have autism or autistic features (20, 22, 48). Autism is associated with greater ED severity, longer-term treatment, risk of admission to intensive inpatient care (49, 50) and negative treatment outcomes (48, 51), further emphasising the need for interventions adapted to their particular requirements. However, there are no separate guidelines for the treatment of EDs in people with autism (49) and approaches to treatment have typically been informed by individual clinician experience (52). It is worth noting, given the relatively high prevalence of autism in those with EDs, that many of the published treatment studies will have included autistic individuals. What is lacking is further research evidence to identify adaptations that may improve treatment efficacy in this group.

Starting in 2017, the views of individuals with autism-AN, carers and clinicians were collected in a series of interviews conducted as part of a wider clinical improvement project by South London and Maudsley NHS Trust (49, 52). The sur-

veys identified a set of priorities for adjustments to routine care and clinician engagement with people with autism-AN (49, 50, 52, 53). The main conclusions are summarised in Box 1.

Box 1. Outcomes of needs assessment for the treatment of autism-AN according to patients, carers and clinicians (49)

1. Importance of recognising sensory differences
2. Recognition that therapeutic engagement with therapists takes longer to achieve
3. Need for an individualised and flexible approach to treatment
4. Difficulty in receiving a diagnosis
5. Lack of a clear treatment pathway
6. Need for clinician training and support
7. Need for adjustment to outpatient and inpatient treatment environments to reduce stress

The themes identified formed the basis for the development of the first specialised care pathway for EDs in people with autism, the "PEACE" pathway (see earlier). Changes to the clinical care model that were introduced as a result included: autism training for ED specialist clinicians, including the use of autism assessment tools; adaptation of treatment approaches and environments for people with autism; development of psychoeducation materials for patients; and enhanced clinician and carer support (49). Within two years of the introduction of the pathway, the mean duration of hospital admission for patients with autism-AN had fallen from 133 days to 90 days, with an attendant reduction in the cost of each admission of almost £23,000 (54). Preliminary indications also suggest a reduction in readmission rates, although data are yet to be published. The success of the project has led to interest in its further development with the aim of expanding the service to patients with autism and EDs other than AN (49), and to those in different treatment settings. In the following section, the development and implementation of the PEACE pathway within community child and adolescent mental health services (CAMHS) is described in more detail and key learning shared to enable further dissemination of this approach.

3. Development of the Buckinghamshire, Oxfordshire and Berkshire (BOB) PEACE initiative

3.1 Background and inception

Following the positive outcomes reported by the South London and Maudsley group in adapting care for autistic adults receiving inpatient treatment for AN, there has been much interest in expanding the PEACE initiative to benefit a wider group of patients. The pioneering work in South London and Maudsley demonstrated that a specific focus on improving care for this group can greatly enhance treatment outcomes and care experience (55). In our local child and adolescent ED services, we observed that young people – especially girls – often present with an ED first, before their autism is recognised. This is in keeping with recent research findings (7, 52). In addition to this, there is a risk that the common restructuring of CAMHS into specialist pathways, while carrying obvious advantages, can disadvantage those with overlapping needs by potentially separating different areas into "silos" of expertise, including neurodevelopmental conditions and EDs. Clinicians working in ED services noted the importance of enabling the identification of autism earlier in an individual's treatment journey and the need to adjust standard treatment protocols to consider suspected autism. This is described by the second author, below.

"I've always felt different, odd, like I didn't belong in the world. I didn't understand why for years. Not knowing why led me to believe I was broken, flawed, wrong. My mental health nose-dived, along with my self-confidence, and I developed anorexia at 14. I spent nearly a decade in services feeling like I was going nowhere, if anything, getting worse. Years spent in hospitals experiencing invasive treatment methods, every possible medication and therapy tried, I genuinely believed I was just broken beyond repair and that there was no chance of it ever getting better.

That all changed when autism was proposed. At first, I didn't accept it – I had a narrow stereotype of what autism was and I didn't fit it. but eventually I did my research and it felt like finally, something made sense. I finally understood why I felt the way I did, why I processed the world in a different way to those around me, why I struggled with aspects of life but excelled in other areas too.

Having my autism recognised meant reasonable adjustments were made within my eating disorder treatment too, which initiated firm strides in my recovery. After 10+ years of going around in circles, I started making real progress.

Since receiving my autism diagnosis, my life has changed significantly. Some of this has been obvious external things, like sensory adaptations, having more time to process change and using different ways to communicate. But the biggest and most meaningful changes have been those I've felt within myself. I stopped being so harsh with myself, so angry. I started feeling compassion to my younger self, discovering who I truly am, advocating for my autistic needs and discovering my autistic identity.

Discovering I was autistic saved my life, but it has also given me a life because the explanation it offered has guided me to not just survive but thrive."

On the basis of these observations and experiences, a group working within the BOB Integrated Care System (ICS) secured three years of NHS innovation funding in 2021 to extend the benefits of the PEACE initiative to children and young people in a community setting. Within this ICS, two provider Trusts deliver three county-wide child and adolescent eating disorder teams, covering a population of approximately 1.8 million. In the BOB PEACE project, we

set out to improve local care pathways for autistic young people with eating disorders by raising awareness of the needs of this group and supporting the integration of expertise to facilitate better care. The aim of the project was to identify, evaluate and disseminate changes in practice that could then form part of an ongoing core offer. To deliver this project we recruited, to a specialist PEACE implementation team of clinicians, experts by experience and support staff. This group worked both across the ICS footprint to transform care as well as developing a local offer embedded within our existing CAMHS ED services. The project was organised into three workstreams: (1) developing early help for autistic young people at risk of developing an ED; (2) improving the identification and experience of autistic young people first accessing ED services; and (3) enhancing the care of autistic young people with complex needs already receiving treatment.

Building on the South London and Maudsley findings outlined in Box 1, above (49), and additional local needs identified through early scoping work, the BOB PEACE project developed a range of interventions to address the additional challenges that may be encountered by patients, families and clinicians and services when working with an ED in the context of autism (see Table 1).

3.2 Identified shortcomings in existing eating disorder management for people with autism and specific aims of the BOB PEACE Pathway

3.2.1 Autism not routinely screened for in eating disorder services

Prior to the implementation of the PEACE project, we did not know how prevalent autistic traits were in our local children and young people (CYP) ED population. Moreover, as a service, we observed that autism was often not recognised as early as it could be in ED treatment. This is in keeping with the research literature (57). Therefore, an early adaptation we made was to introduce the AQ-10, a short 10-item screening measure of autistic traits. Using this measure, alongside a standard clinical assessment interview, enabled us to identify any reasonable adjustments for

Perspective	Challenge identified	PEACE intervention
Service level and clinicians	Autism not recognised early in treatment history, leading to poorer experience and outcomes.	Introduced screening and training for clinicians; PEACE champion roles embedded within ED teams; early-help resources developed and disseminated via dedicated website.
	Lack of confidence in ED services in identifying autism, and in neurodevelopmental services in treating EDs.	Strengthened links between neurodevelopment and ED services to ensure integrated care; complex case panel set up.
Service level	Ensuring our eating disorder services are neuroinclusive and in line with key standards.	NAS accreditation achieved, resulting from improvements to clinical settings, reasonable adjustments offered and inclusive care plans.
	No specific resources offering early help to autistic CYP at risk of developing an ED.	Psychoeducational resources developed and distributed to schools and doctor surgeries.
All	Evidencing improved outcomes and care amongst autistic CYP with eating disorders.	Clinical outcome measures indicated improvement in CGAS, GBOs and reduction in risk for CYP.
	Missed opportunities to learn from lived experience and improve care.	Patient and parent EbyEs embedded in PEACE throughout the project.
CYP, clinicians and carers	Communication between CYP and clinician, and within the families.	Communication passports completed and embedded into care plans; advocating different styles of communication.
Service, CYP and clinicians	Sensory processing differences not accommodated for by traditional ED treatment models or are they accounted for in the clinical environment.	Reasonable adjustments webinar series delivered surrounding sensory sensitivities with regard to food and meal plans. Sensory boxes were put into clinic waiting rooms and appointment rooms.
CYP	Loneliness, social difficulties and masking commonly described by autistic individuals, which have been identified as causal and maintaining factors for an ED (56), and not addressed by current treatment pathways.	Low-intensity interventions were designed to explore how autistic people could learn to unmask, empower their autistic self and find connections with others.
	Preference for sameness and routine, with difficulties in navigating and tolerating change.	PEACE advocates for using the strengths of the autism, such as the ability to plan and adhere to plans, in recovery. Additionally, low-intensity intervention was created surrounding skills for tolerating uncertainty and change.

Table 1. How the BOB PEACE project set out to improve care for autistic children and young people with eating disorders

Abbreviations: CGAS = Children's Global Assessment Scale; CYP = children and young people; EbyEs = experts by experience; ED = eating disorder; GBO = goal-based outcomes; NAS = National Autistic Society; PEACE = Pathway for Eating disorders in Autism developed from Clinical Experience

possible autism to be made early in their care, improving their experience of services (52). It is important to note that starvation-induced changes can mimic some features commonly seen in autism. Our approach was needs-led rather than diagnosis-led, and any reasonable adjustments were made and reviewed following collaborative conversations with the young person and their family. We know from the original London study that many of the reasonable adjustments were beneficial to patients irrespective of autistic status and did no harm. As a secondary benefit, introducing screening allowed for early referral for neurodevelopmental assessment in cases where this was deemed appropriate.

3.2.2 Lack of confidence in managing autism and eating disorders

Toward the start of the BOB PEACE initiative, a training needs analysis revealed that expertise across EDs and autism had become increasingly "siloed" with the development of specific CAMHS pathways. Neurodevelopmental teams lacked confidence in identifying and responding to ED needs, and clinicians in ED teams lacked knowledge and confidence around autism. In addition, the overlap of EDs and autism was poorly understood. Therefore, the project set out to offer information, training and resources to bridge the knowledge and confidence gaps across teams. This included offering monthly webinar training for different areas of the overlap between autism and EDs, publishing a monthly newsletter, developing a website where information could be disseminated and creating resource leaflets on different aspects of the overlap, such as emotional processing and sensory needs.

The monthly webinars were extremely successful, with between 60 and 150 attendees each month. Topic areas addressed included: communication differences, the interplay between autism and EDs, spotting the signs, reasonable adjustments that could be made to standard family therapy for anorexia nervosa and supporting autistic young people with EDs in school.

Webinars were well attended and got excellent feedback.

"The webinar was absolutely amazing! It was informative and [speakers] were brilliant! Have gained lots of valuable knowledge through the webinar!"

"Great to have expert clinicians and researchers presenting. So valuable listening to the experts by experience – brilliant contribution from them."

Both the website and monthly newsletter contained more information and insights gained throughout the project, as well as achievements and progress made as a PEACE team. The website offered information on the overlap between autism and EDs through lived experience videos, animations and pages to read, alongside resources for clinicians to access when working with an autistic or possibly autistic young person.

3.2.3 Empowering clinicians and carers in autism and eating disorders

A goal for the BOB PEACE team was not only to improve the service experience for the young person, but also to empower clinicians treating young people who they suspected were autistic. As a team, this was achieved through information dissemination and resources, but also through direct involvement of PEACE clinicians in consultations, assessment and care planning, tailoring evidence-based interventions and supporting autism assessment referrals.

Direct work had very positive outcomes; below are quotes from clinicians and carers.

"I now have a clear plan and knowledge to confidently support this young person, which includes signposting, giving resources and advice around psychoeducation, and setting up a communication passport." (clinican feedback)

"After battling for many years, this is the first time my child has responded so positively to treatment."

"The PEACE team have brought a unique understanding of my daughter's [autism spectrum disorder] and anorexia, and the complex relationship between the two." (parent/carer feedback)

Figure 1 demonstrates the positive impact PEACE had on clinicians' understanding of the overlap between autism and EDs and the efficacy of direct consultation work.

3.2.4 Ensuring eating disorder services are neuroinclusive and in line with key standards – National Autistic Society accreditation

Demonstrating the commitment of ensuring our services are neuroinclusive, and as an external marker of the reasonable adjustments described, we sought and achieved National Autistic Society (NAS) accreditation across all three ED services. These included adjustments such as: sensory accommodations in clinic settings, an active approach to adapting therapies and treatment approaches with autism in mind and the development and distribution of resources about autism, EDs and the overlap. This also has the benefit of communicating our neuroaffirmative ethos to new CYP and families and inspiring other parts of the CAMHS system to do the same.

3.2.5 No specific pathway offering early help for autistic people at risk of developing an eating disorder

It is well documented that autistic individuals are at a greater risk of developing mental health problems, including

EDs (58, 59). We aimed to improve the knowledge and understanding of why autistic people may develop EDs, help parents and carers to spot the early warning signs of disordered eating and EDs and provide advice on avenues of support for CYP and those supporting CYP. One of the biggest achievements of the innovation project was raising awareness of the needs of this group and how care can be improved using the PEACE framework.

This was achieved through creating psychoeducational resources offering information on why autistic people may be at a higher risk of developing an ED and when difficulties with food may need a more intensive support intervention. Further information was also disseminated through the monthly newsletter and accessible on the website for ease of access. Many of these resources were also shared with schools and GP surgeries to ensure autistic CYP were offered neuroinclusive care and reasonable adjustments as early on into their experience of eating difficulties as possible.

3.2.6 Improving outcomes and care experiences

Prior research had indicated that without reasonable adjustments, autistic people are more likely to have a negative experience of ED treatment and poorer outcomes than their neurotypical peers (48-50). Thus, it was important to monitor clinical outcomes to ensure the care provided was effective and beneficial. Our outcome measures indicated improvements across the Children's Global Assessment Scale (CGAS) and Goal Based Outcomes for CYP utilising the pathway. CGAS measures completed to date showed that 85% (n = 13/15) of the young people with the highest level of need, receiving direct support from a PEACE clinician, showed an improvement in in overall functioning between pre-PEACE and post-PEACE intervention scores. In our initial pilot of the targeted modular interventions delivered by assistant psychologists, 100% (n = 14) demonstrated improved scores following delivery of the module, highlighting that all young people felt closer to achieving their individualised goals. Following PEACE consultations, clinicians reported at least one improved outcome (reduced admission length, need for escalation or risk to/from self and others, improvements to physical health, or improvements in engagement with the young person) in 77% (n = 114) of cases. Of applicable high-risk cases receiving PEACE consultation, clinicians reported a reduction in the length of admission to paediatric or acute inpatient care or crisis services in 42% (n = 5) of cases, and reduced need for escalation or admission to paediatric or acute inpatient care or crisis services in 47% (n = 9) of cases. Of the responding clinicians, 94% (n = 46) also reported better understanding of their young person's needs following PEACE input, with 80% (n = 39) reporting increased confidence in working with the young person and 86% (n = 42) reporting that PEACE input led to a better treatment plan being developed. Furthermore, qualitative feedback from both patients and parents/carers of CYP with EDs reflected the positive impact of PEACE, captured by the quotes below.

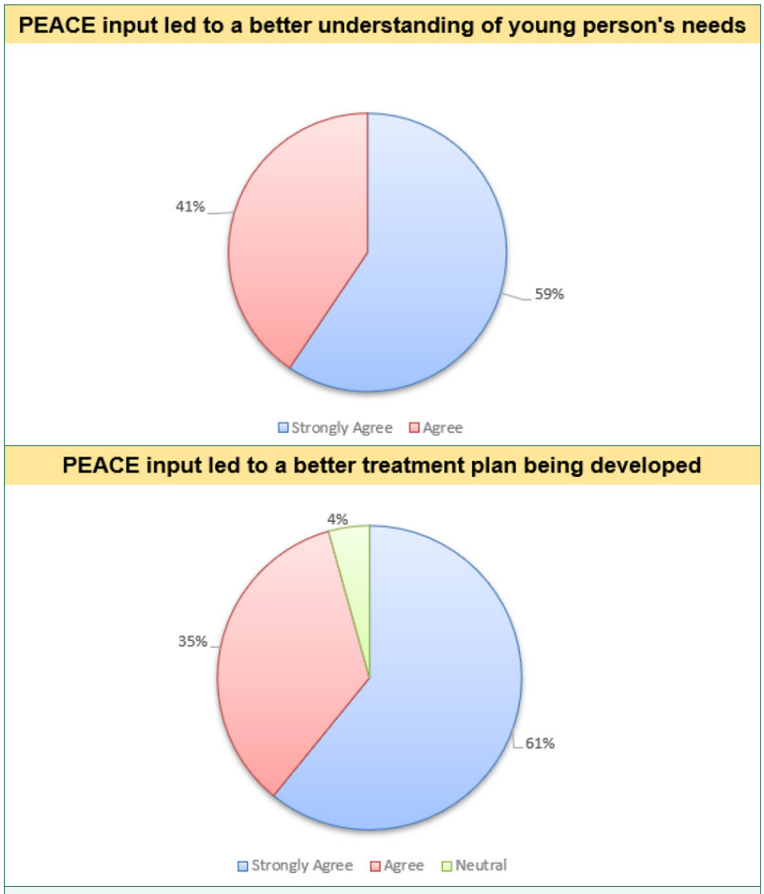

Figure 1. Distribution of responses to key clinician feedback questions

"My daughter has had four years of inconsistency of care, leaving her feeling hopeless and that the system doesn't care. At last, she feels that she has found someone who truly understands her needs."

"As my daughter would not engage directly with any professionals, the PEACE clinician has had regular sessions to advise and coach me in how best to support her. These sessions have been invaluable and have been a significant part of my child's steps towards recovery. The PEACE team have brought a unique understanding of my daughter's ASD and anorexia, and the complex relationship between the two."

3.2.7 Missed opportunities to learn from lived experience

Recognising and listening to the voices of those with lived experience of EDs, and autistic individuals, has been advocated for in recent years in response to a lack of evidence for treatment efficacy (7) and meaningful change in understanding the conditions (60, 61). The inclusion of lived experience has been found to promote inclusivity of otherwise relegated voices, reduce the power dynamic between service providers and users and offer inspiration for recovery (60, 62).

In light of this, Experts by experience (EbyEs) were embedded in the PEACE project throughout, encompassing a wide range of tasks and responsibilities. For example, representation on the project board; co-producing project workstreams; speaking at conferences and contributing to the webinar series; offering continuing professional development training slots; answering clinicians' questions; assisting in the research being conducted; helping design and produce the website, newsletter and resources; and helping develop the low-intensity therapeutic interventions. The feedback from clinicians of having the lived experience perspective was profound, often referred to as the most helpful aspect of training and learning. EbyEs were able to offer valuable insights into their experience and presentation of their EDs as autistic individuals, specifically surrounding symptomology that may not align within traditional diagnostic frameworks, enabling a broader understanding of EDs and facilitating relevant considerations for diagnosis and treatment. Furthermore, the EbyEs reported feeling heard and validated as well as having improvements to their own recovery journey and self-understanding through using their lived experience to shape treatment and research.

3.2.8 Communication differences

The social communication difficulties that autistic people experience may impact their ability to engage in treatment, especially due to the heavy reliance on verbal articulation and conversational interaction within traditional ED treatment, such as in therapy. Clinicians had identified that communication differences made building rapport more difficult (50), and parents have expressed how the types of language used impacted their child's engagement with services (57). Alongside this, autistic people expressed the benefit of adaptations made to typical communication styles to meet their needs, such as offering written information (57). It is important to note that autistic people can benefit just as much from evidence-based treatment models when additional consideration is given to how these are communicated and other aspects of care, such as the therapy environment.

PEACE advocated the use of communication passports which explore how an autistic person prefers to communicate, such as through writing or art, alternative ways of communicating how they are feeling and areas in which they need more support. Communication passports have previously been shown to be effective for patients with EDs, as well as those with co-occurring autism and EDs, by documenting their communication preferences and offering insights into their identity and who they are outside of the ED (63). Communication passports were completed for each CYP seen and embedded into care plans so that each clinician was able to access and make reasonable adjustments when working with the young person.

Additionally, training was delivered to clinicians about the importance of using clear, unambiguous language and refraining from using metaphors or abstract concepts that autistic people may find more difficult to understand (64).

3.2.9 Masking and social interactions

Difficulties in social interaction are commonly reported among autistic individuals; struggling to fit in, bullying and loneliness have been found to be directly and indirectly linked with the development of EDs (56). Moreover, autistic people may engage in masking or camouflaging behaviours to try to gain social acceptance and fit in with peers. The negative impacts of masking are multifactorial, including exhaustion leading to "burnout", anxiety and depression. These negative impacts can impede identity development and have been found to predict ED symptomology (65). These may act as additional maintaining factors which receive less attention in traditional models of treatment. We developed additional modular interventions of one to seven sessions, deliverable by assistant psychologists or similar staff, to address these specific areas of challenge. These modules were developed to be delivered alongside routine treatment to address areas identified as important to a specific young person. We are currently in the process of evaluating their efficacy.

In CAMHS services, it is important to consider the young person's social experience, especially in navigating the school environment. As a PEACE team, we developed a four-session modular intervention called "Finding Connections", which explored what masking is and its impact, empowered the young person to feel able to unmask and explored ways to find and make them feel connected to others as their authentic autistic self.

For clinicians, a webinar was delivered offering information on masking and the impact of masking for autistic people, and strategies that could be used to encourage an autistic person to feel able to unmask.

3.2.10 Sensory processing differences

Differences in sensory processing experienced by autistic people can include being hypersensitive and hyposensitive to stimuli and sensations (1, 66). For an autistic person experiencing an ED, this may be shown through a limited variety of foods being deemed "safe" due to their texture or temperature, struggling to process busy, noisy and bright waiting room areas in hospital settings and being hypersensitive to feelings of fullness and bodily sensations. Hyposensitivity may incorporate difficulties in recognising and interpreting interoceptive cues, such as bodily signals of hunger and thirst. Autistic individuals have expressed the importance of understanding and accommodating for sensory processing differences in ED treatment, where it currently does not (52, 53). Moreover, a lack of sensory processing adjustments can impede an autistic person's ability to adhere to treatment (57) and may cause individuals to feel unable to engage in treatment due to overstimulating clinical spaces (67).

In response to this need, PEACE offered information and resources to improve the understanding of the autistic person's sensory world and how this may impact eating behaviour. It also facilitated making reasonable adjustments within the clinic environment and dietetic support with meal planning and food preferences. This was done through delivering webinars with ideas on how to make clinical areas autism friendly; a "sensory checklist" was also developed as a quick guide for clinics to refer to, so as to ensure that sensory accommodations were being made.

Within BOB ED services, clinic settings were de-cluttered with an optional quiet waiting area. Sensory boxes were put into all waiting rooms, with the option of using sensory tools within appointments to help the autistic person regulate themselves. For young people, a three-session modular intervention was made with information about their autistic sensory world, understanding and advocating for their sensory needs.

3.2.11 Preference for sameness

Autistic people may rely more heavily on a routine and struggle with change more than their non-autistic counterparts (68). Understanding that effective planning and predictability can help an autistic person meant that it was important for PEACE to implement strategies that work with the autistic mind to aid their recovery.

In ED services, clinicians were informed of the importance of making and adhering to plans made with the autistic young person, and to give as much notice as possible about any upcoming changes. It was advised that meal plans may be required for a longer amount of time than for non-autistic individuals, and changes in treatment may occur at a slower rate. Importantly, it was highlighted that an autistic person's preference for sameness does not mean that evidence-based treatment would be more difficult or less effective, as effective planning can actually improve treatment adherence, as supported by previous literature (69).

Where change does need to occur, especially during the initial stages of treatment, the individual is trained in additional skills around tolerating uncertainty and change, delivered through a further modular intervention.

3.3 The process in practice: a case example

The efficacy of the direct PEACE approach that clinicians were able to offer and implement has been captured in case studies, such as the one described below.

J was a 13-year-old girl who presented to the local paediatric ward following a deterioration in her physical health having engaged in significant dietary restriction over the course of several months. J was suspected to be on the autistic spectrum and was already waiting for a diagnostic assessment by the local neurodevelopmental team.

The PEACE clinician joined the primary ED assessment, which took place on the ward, offered an initial consultation and agreed ongoing complex consultation. J and her family struggled significantly with managing discharge from the paediatric ward and J required a lengthy second admission. The PEACE clinician brought a combined knowledge of autism and EDs to support effective multidisciplinary working, with the aim of avoiding admission to an inpatient psychiatric hospital.

Professionals' meetings commenced weekly, including both ED and neurodevelopmental staff to support thinking around discharge from the hospital. Paediatric staff became instrumental in helping achieve this. Following J's successful discharge and improvement in her physical health, avoiding psychiatric admission, the PEACE clinician supported access to a formal neurodevelopmental assessment. The PEACE clinician continued to offer regular contact with J's parents, alongside her key worker, to complete her transition back to community treatment.

The positive impact of the indirect interventions and adaptations from PEACE pathway has also been captured, reflected in the feedback from a patient below:

"The work that PEACE do save lives like mine. By raising awareness of autism, we can better identify those who are autistic and sooner. Implementing reasonable adjustments for autistic individuals in eating disorder treatment pathways improves engagement, patient experience and recovery outcomes. As an autistic patient, I can only celebrate the work that PEACE does and is doing."

3.4 Reflections, learning and future directions

On reflection, many of the targets set out at the beginning of the BOB PEACE innovation project were achieved. At the end of our three-year innovation period, most clinical staff working in CAMHS and Adult Eating Disorders were aware of the PEACE initiative and related resources. This impact continues to help empower clinical staff to identify possible autism and make reasonable adjustments early on in care. As most experiences of mental health difficulties begin in childhood and adolescence (70), enabling a positive experience of help-seeking and treatment can be crucial in creating positive mental health outcomes both in childhood and later life. We have accrued initial evidence that a proactive, neuro-affirming approach to ED treatment in CAMHS can improve treatment experience and potentially both reduce risk and shorten or avoid higher-intensity treatments, such as hospital admission. This is particularly important as inpatient admissions can carry additional risks to the wellbeing of autistic people, including the risk of a poorer outcome. Our project was not about changing the core evidence-based treatment models, many of which probably included autistic people in their research studies. Instead, it set out to support those delivering treatment

to do so in an autism-informed capacity. Achieving NAS accreditation was a key achievement in evidencing this approach. Qualitative feedback and case studies, such as the one previously described, indicate the positive impact the project has made. We acknowledge that autistic individuals often present with atypical symptomatology that does not align neatly with traditional diagnostic frameworks. This requires the need for ongoing flexibility in diagnostic and treatment approaches, such as those set out in this paper. We hope that demonstrating the positive influence of being curious about autism in ED treatment and the initiatives of PEACE will continue across relevant mental health services.

An aspect that proved integral to the PEACE implementation was the embedding of people with lived experience from the beginning which was repeatedly cited as a highlight of the training and psychoeducational content delivered. Our innovation project acted as a flagship for the value of including lived experience in service design and improvement and inspired other areas to do the same. We were also struck by the positive personal impact on the EbyEs, who contributed so much to the project's success.

Capturing the impact of PEACE-driven changes was not always easy. Evidencing impact across heterogeneous individuals in a complex multifaceted treatment system is correspondingly complex. We are aware we may not have captured all aspects of intersectionality between autism and EDs, for example, the intersection of physical health, particularly gastrointestinal conditions (71) and broader demographic factors such as ethnicity and socioeconomic status. We undoubtedly developed more effective ways to capture impact as the project developed over its three-year lifespan. This meant that we missed some opportunities fully to evidence impact early on in delivery. While our data were able to demonstrate a positive effect, we recognise that even with additional funding and staff resource, evidencing value in busy NHS settings can be a challenge. We hope that by disseminating our findings, this will support commissioners and service providers in other areas to adopt and continue to evidence the effects of the PEACE initiative.

Our final area of work has been to embed findings from the funded project into the core service offer, so that future CYP, families and staff continue to benefit from the innovative work, resources and knowledge accrued. Innovation funding was fundamental to allow us to adapt and demonstrate the benefits of PEACE in our community CYP population. However, we leave a legacy of a care delivery model, website, adaptations and resources that other providers can adopt easily with minimal cost to benefit many more autistic CYP and adults and their families who are struggling with EDs. Arguably, this is, perhaps, our greatest achievement.

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