Graham *et al. Discover Mental Health* (2025) 5:200
https://doi.org/10.1007/s44192-025-00340-0

Discover Mental Health

**RESEARCH** **Open Access**

# A thematic analysis of the views of neurodivergent women with a personality disorder diagnosis on clinical pathways within mental health services

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## Abstract

**Purpose** Adults with a personality disorder diagnosis have a high prevalence of co-occurring autism and attention deficit hyperactivity disorder (ADHD). However, there is often no defined pathway within mental health services to meet the needs of this population, and a lack of evidence or consensus on the optimal approaches to identification, treatment and support for neurodivergent people with a personality disorder diagnosis. There has been little exploration of the views of this population on the care they receive in community mental health services. Therefore, the aim of this project was to understand the experiences and perspectives of neurodivergent people with a personality disorder diagnosis, to inform a clinical pathway which is effective, safe, sustainable and equitable.

**Methods** Ten qualitative interviews were conducted with women with a diagnosis of, or had been referred for a diagnosis of, autism or ADHD, and a diagnosis of personality disorder. Interviews were analysed using reflexive thematic analysis.

**Results** Five key themes emerged; staff factors (understanding and skills, attitudes and communication), pathways and processes (access to services and barriers to support), involving and enabling (through adaptations and empowerment), support and clinical interventions (experience of individual therapies and groups, and opportunities to evaluate support), and diagnosis and identification (the impact and accuracy of diagnosis).

**Conclusions** This study highlights gaps in current practice as well as personal preferences about identity and experiences of misdiagnosis. It identifies the components of an integrated clinical pathway, that include a person-centered, formulation-driven approach to assessment and reasonable adjustments; peer-led psychosocial support; adapted transdiagnostic psychological therapies; and embedded co-production. Clinical and research priorities are discussed.

**Keywords** Neurodivergence, Personality disorder, Clinical pathways, Autism, ADHD, Misdiagnosis

## 1 Introduction

Neurodivergence is an umbrella term which includes both autism and attention deficit hyperactivity disorder (ADHD)[1, 2]. There has been recent focus on symptomatic overlap and frequent co-morbidity between autism/ADHD and personality disorders [3]. The World Health Organisation's International Classification of Diseases (11th Edition) (ICD-11), uses a dimensional approach to define personality disorders, describing them as an enduring disturbance characterised by problems in functioning of aspects of the self (e.g., identity, self-worth, accuracy of self-view, self-direction), and/or interpersonal dysfunction (including ability to develop and maintain close and mutually satisfying relationships, ability to understand others' perspectives and to manage conflict in relationships). They are classified within three levels of severity and one or more prominent trait domains [3, 4].

Personality disorder can be a highly stigmatising diagnosis, and there is significant controversy around its use as a diagnostic label [5]. In particular, borderline personality disorder (BPD), is subject to considerable controversy about its construct validity, in part because of the gendered nature of the diagnosis, high prevalence of trauma exposure in this population and structural stigma regarding legitimacy and treatability [6, 7]. However, some people with a personality disorder diagnosis view it as a validating and helpful way of understanding and communicating their difficulties. They also highlight that lack of recognition prevents access to, and development of, effective evidence-based psychological treatments, and can maintain stigma and marginalisation of people with this diagnosis [8, 9].

There has been recent focus on symptomatic overlap and frequent co-occurrence between autism/ADHD and personality disorders [10]. For adults presenting to mental health services with serious mental health conditions, there is likely to be a high prevalence of autism and other neurodevelopmental conditions, although these may be undetected [11–13]. Similarly, a growing body of research suggests that people diagnosed with personality disorders often have neurodevelopmental conditions, including autism and ADHD, and that co-occurrence is common within clinical populations, to the extent that some authors have argued that borderline personality disorder be conceptualised as within a neurodivergent framework [10, 13]. Other authors have questioned the construct validity of personality disorder in neurodivergent people due to overlap within diagnostic criteria [14].

Researchers and lived-experience activists have highlighted that misdiagnosis and diagnostic overshadowing is common, particularly in women and girls presenting to mental health services [10, 15–17]. Validated screening and assessment tools are poor at discriminating between these conditions in clinical populations, with long waiting times for screening and diagnosis within specialist services [18–20]. Neurodivergent individuals are likely to have different, increased, and often unmet mental health needs, compared to 'neurotypical' individuals [21, 22], which may impact their access to appropriate mental health services and their treatment outcomes [23].

Both neurodivergent adults and those meeting criteria for a personality disorder diagnosis face multiple barriers to accessing care, siloed pathways, a shortage of services for complex presentations and exclusions based on both diagnoses [18, 24]. Clinicians may lack training and experience with either client group, contributing to the 'triple empathy' problem, where communication difficulties between autistic individuals and clinicians are exacerbated by a third layer of empathy breakdown—between patients, doctors, and the health care system itself [25, 26]. People with personality disorder diagnoses face additional structural stigma towards the condition [27].

Despite these issues, there is an expectation that mental health services are accessible and acceptable for neurodivergent people through tailored local strategies, training the workforce, and implementing reasonable and universal adjustments [28]. Moreover, there is growing recognition of the need for neurodiversity-affirming practices to be adopted in clinical interventions [22, 29]. There is a limited but growing evidence base demonstrating the efficacy of psychological therapies for borderline personality disorder, that have been modified for neurodivergent people with co-occurring personality disorder diagnoses [30–32]. However, research has highlighted the need for improved pathways and adapted clinical practice [33, 34]. Despite this, there is a lack of consensus on how best to identify, make adaptations for, and support patients with a personality disorder diagnosis, who also have co-occurring, misdiagnosed or undiagnosed neurodivergence [35]. There is also a lack of clarity about the optimal approach to the design of clinical pathways for people with these co-occurring conditions [36, 37].

Therefore, the aims of this study were to gather an in-depth understanding of the experiences of neurodivergent adults who have received a diagnosis of personality disorder, or who have received interventions for 'complex emotional needs', in accessing care pathways within a National Health Service (NHS) mental health trust within the South-East of England. It aimed to explore their views on the barriers and facilitators to effective care, and their perspectives on the components of an optimal pathway for co-occurring autism/ADHD, and personality disorder/'complex emotional needs'. These findings will then be used to inform a co-designed clinical pathway for neurodivergent people with a diagnosis of personality disorder, that will then be piloted and evaluated in subsequent research.

## 2 Materials and methods

### 2.1 Study design

This qualitative research incorporated semi-structured interviews with ten neurodivergent women with a diagnosis of, or referred for a diagnosis of, autism and/or ADHD, and with a diagnosis of personality disorder. In-depth interviews explored the experiences of participants across existing clinical pathways in community services in a National Health Service (NHS) mental health trust in the South-East region of England. Colleagues from the Trust's Reasonable Adjustments Service (RAS) with lived experience and professional experience of neurodivergence, were part of the working group and co-produced all elements of the project. One of the authors of the paper is a neurodivergent woman with a personality disorder diagnosis and has been involved throughout the project.

### 2.2 Theoretical underpinning and methodology

This research adopted a social constructivist approach, theorising that learning is collaborative and knowledge is acquired from our interactions with others. This positioning enabled the authors to move away from a deficit-focused approach and acknowledge the role of external social, cultural and environmental factors [38]. A reflexive thematic analysis [39, 40] was used to allow a combination of researchers' theoretical assumptions and interpretative analysis of the data set [39, 41]. Of the proposed theoretical assumptions in reflexive thematic analysis, a predominantly inductive approach was utilised to ensure open-coded data and an emphasis on data-based meanings.

An element of deductive analysis was also incorporated to ensure relevancy of interpretations and data-based meanings to the research questions [42]. According to the essentialist approach, the assumption was made that meanings and experiences disclosed by respondents were reflected by the language used. Additionally, the semantic approach was adopted for coding; however, some hidden meanings and assumptions were also identified, beyond the descriptive level of data. The coders' positionality (including biases of working within mental health services and holding prior beliefs about the limitations of the current pathway) were considered throughout the analytical process and mitigated through team-based coding and external auditing in theme development.

### 2.3 Setting

This project was carried out with service users with experience of NHS England Community Mental Health Services in the South-East region of England.

### 2.4 Participants and recruitment

Individuals had a diagnosis of, or had been referred for a diagnosis of autism and/or ADHD (80% Autism diagnosis, 10% awaiting Autism diagnosis, 10% Autism and ADHD diagnosis) and reported receiving a diagnosis of personality disorder (90% diagnosis of Emotionally Unstable Personality Disorder/Borderline Personality Disorder (EUPD/BPD), 10% assessed as having 'traits of' EUPD). All participants had experience of seeking support from community mental health services. Purposive sampling was initially used, as respondents were approached by colleagues, provided with a brief description of the study (including aims and background), and given contact information for the research team. Snowball sampling was also incorporated as respondents shared the project information sheets with service user forums. Overall, ten participants were recruited, all identified as female (and were assigned female at birth), mean age was 41.6 years (range 26–59), ethnicity was 80% White British, 10% White Scottish and 10% White Other (Table 1). Overall, thirteen service users expressed interest in participating, and ten volunteered and provided consent.

**Table 1** Participant Characteristics

| Participant ID | Age | Self- reported Gender | Ethnicity | Neurodivergent Diagnosis | Personality Disorder Diagnosed/ Assessed |
|---|---|---|---|---|---|
| 1 | 40 | F | White British | Autism | Yes |
| 2 | 27 | F | White Scottish | Autism | Yes |
| 3 | 55 | F | White British | Autism | Yes |
| 4 | 52 | F | White British | Autism | Yes |
| 5 | 51 | F | White Other | Autism | Yes |
| 6 | 26 | F | White British | Autism | Yes (assessed as having 'PD traits') |
| 7 | 37 | F | White British | Autism | Yes |
| 8 | 59 | F | White British | Autism | Yes |
| 9 | 43 | F | White British | Autism and ADHD | Yes |
| 10 | 26 | F | White British | Awaiting autism assessment | Yes |

Information power for sample size is calculated by considering the aim of the study, the specificity of research questions, data analysis methodology, the quality of the interview dialogue, and the diversity of interviewees [43]. From these characteristics, the sample size of ten participants was considered to provide sufficient information power to develop initial themes, that will contribute to the design and testing of a co-produced clinical pathway within an NHS Mental Health Foundation Trust.

### 2.5 Data collection

Prior to interviews, information sheets were given, with the opportunity for participants to ask questions before giving informed consent. Interviews were conducted between March – June 2024 and conducted online on Microsoft Teams (excluding one participant who opted for a face-to-face interview) to improve accessibility as the participants reported a preference for online versus face-to-face interviews [44]. A topic guide for interviews was co-designed by mental health staff and people with lived experience (Appendix B). A pilot was incorporated to ensure questions were clear and appropriate. Interviews lasted around 60 minutes and incorporated reasonable adjustments (such as questions being shared with the participants prior to the interviews and having the camera off) to reduce stress, promote safety and increase empowerment [45] (See Appendix A). Flexible semi-structured interviews allowed participants to lead the discussion and identify key focus areas. The following topics were explored in the interviews: screening and assessments, diagnosis and post-diagnostic support, therapies and interventions, reasonable adjustments, and experiences of services. With participant consent, the interviews were video-recorded and transcribed on Microsoft Teams. This was stored on a password-protected computer, with restricted access permissions, and separate from identifying data. Permissions for this project were granted by the NHS trust in the UK in which the study was undertaken. The project was registered with the NHS Trusts' Quality Improvement Hub. Written consent was obtained from all participants.

### 2.6 Data analysis

The six steps of reflexive thematic analysis were conducted as outlined by Braun and Clark [42]. This included familiarisation with the data, generating initial codes, generating themes, reviewing potential themes, defining and naming themes, and producing the report. The automated transcriptions of interviews on Microsoft Teams were reviewed to ensure accuracy of transcription and to produce non-verbatim transcripts for analysis. This was carried out by five members of the research team. The edited transcripts were stored on a password-protected computer, with restricted access permissions, and separate from identifying data.

Interviews were then coded by three members of the research team using Nvivo 14 software [46]. After coding one transcript each, the researchers met to consider code definitions and overlap. Multiple coders ensured rigor in analysis and coding and inter-rater reliability. Following this, all other interviews were coded to create a complete list of codes (see Appendix C). Researchers continued to meet weekly to evaluate reflexivity, identify and explore any biases, and to ensure reliability in coding. Initial themes were discussed and reviewed with people with lived experience of neurodivergence and diagnosis of personality disorder. The use of multiple coders is salient in ensuring meaningful

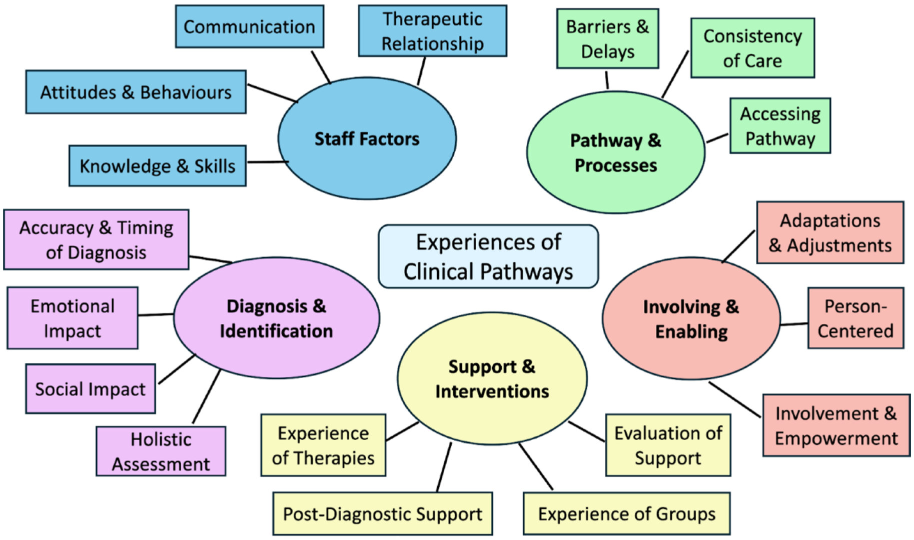

**Fig. 1** Key Themes about experiences of Clinical Pathways

interpretations of the data and ideas, and to build upon theoretical accounts [39]. Overall, a high degree of overlap was evident.

## 3 Results

Five key themes were drawn from the thematic analysis: diagnosis and identification (the impact and accuracy of diagnosis), pathways and processes (access to services and barriers to support), support and clinical interventions (experience of individual therapies and groups, and opportunities to evaluate support), staff factors (understanding and skill, attitudes and communication), involvement and enablement (through adaptations and empowerment) (see Fig. 1).

### 3.1 Diagnosis and identification

#### *3.1.1 Accuracy and timing of diagnosis*

The majority of respondents had initially been diagnosed with a personality disorder, and later as autistic. They felt that this was due to lack of recognition of autism by professionals, exacerbated by increased masking in females and therefore a delay in identification and diagnosis. Some respondents felt that autism/ADHD was a more accurate and validating diagnosis, and rejected their personality disorder diagnosis, although others identified with both. The long delays within specialist services for autism and ADHD assessments were acknowledged, and several respondents suggested that a more holistic, needs-based and formulation-led approach, which included screening for autism/ADHD traits, would have been more helpful, using an integrated screening and assessment process:

> *P2: "It's been long, and I think also because with more potential autism diagnosis, that's complicated things further, because I think some complex emotional needs are coming from the fact that I wasn't diagnosed with autism from a young age."*

#### *3.1.2 Emotional impact of diagnosis*

A major aspect was the emotional impact of the personality disorder label, and the stigma attached to this. Seven participants did not identify with this label, and the harmful impact of stigmatising diagnostic labels was highlighted:

> *P6: "When it came to the personality it made me feel awful like it made me feel so bad about myself and there was no positive element to it. I didn't feel like it fitted, but also it made me think that there was something wrong with me."*

However, others felt that their complex emotional needs were consistent with a personality disorder diagnosis and felt that they had benefitted from evidence-based interventions for BPD. With regards to neurodivergence, respondents described experiencing overwhelm at the idea of this being a lifelong diagnosis. More generally, respondents reported feeling invalidated and struggled with the emotional demand of repeated assessments and disclosure of experiences. To reduce this emotional impact, respondents suggested that clinicians improve communication and transparency about waiting times, information-sharing and pathways, and that effective post-diagnostic information and support is provided. A needs-led, formulation-based assessment process was recommended as an alternative to diagnosis.

#### *3.1.3 Social impact of diagnosis*

This revealed the difficulties respondents have experienced in both social and work environments. For example, there were common concerns around trying to fit in and worrying about how they are perceived by others. This social comparison and 'thwarted belonging' led to increased masking and increased suicidality. Respondents stated that increased validation and compassion for their experiences, as well as improved information and peer-led support would help them to understand and navigate this aspect of their experience:

> *P10: "Say I was with a crowd of people that was not great behaved, I would be copying what they're doing to try and fit into it. That wasn't me as a person, but that's what I felt like I had to copy to be like them."*

#### *3.1.4 Holistic assessment*

Respondents highlighted the need for holistic, integrated assessments within mental health services, in which developmental history is explored. They emphasised the helpfulness of moving to a needs-based, and formulation-centered approach to identify traits and difficulties across the overlapping dimensions of autism/ADHD and personality disorder diagnosis which could then be used to develop individualised care pathways:

> *P4: "Look at all of these labels that I've attracted over the years, also think about the obsessive compulsive and avoidant personality disorders and how that's actually more fitting to an autistic person when you look at it that way."*

### 3.2 Pathways and processes

#### *3.2.1 Barriers and delays*

Respondents highlighted the impact of misdiagnosis and inaccurate assessment of needs. Respondents described repeated assessments, unsuccessful treatment episodes, and withdrawal of care following late identification or diagnosis of autism or personality disorder. Both diagnoses had led to exclusion from services, as well as inappropriate pathways, or re-referral to different services and further long waiting times. Waits of several years for a diagnosis of autism/ADHD from specialist neurodevelopmental services were highlighted, and many said that they were excluded from mental health services whilst waiting for an Autism/ADHD assessment. Overall, respondents reported that they had not been offered an integrated clinical pathway to support with all of their needs and that this had resulted in exclusion, delays and siloed working. This contributed to a mistrust of professionals and of services:

> *P4: "And actually nobody really talks about the fact that if you can't be helped by them, the waiting list isn't six weeks, it's 9 months or more. So, I'd say that's quite difficult, and it also means that it makes discharge really scary because you know how difficult it is to be re-referred in."*

### *3.2.2 Consistency of care*

Overall, respondents reported poor consistency of care across services, particularly across specialist neurodevelopmental services for autism/ADHD and mental health services. Poor communication and lack of integration between services led to respondents feeling unsupported and not listened to. Inconsistent use of neurodiversity inclusion passports (documents for neurodivergent individuals, intended to communicate reasonable adjustments to improve access to and engagement with services) was also reported, with some respondents not having been offered them at all, and others not having reasonable adjustments implemented both within and across services:

> *P6: "You get passed around a lot and that had a really negative experience because it meant that I felt like things were much worse than I thought they were because nobody was saying that they could help."*

### *3.2.3 Accessing pathways*

Similarly to the previous sub-themes of barriers/delays and consistency of care, difficulties with accessing effective clinical pathways were highlighted. Some participants felt frustrated that they had to self-initiate referrals:

> *P1: "I basically had to write all the referral, both the initial one and then a follow up one. But it's taken many months."*

However, overall, there were varied experiences of accessing pathways, with some participants reporting positive experiences, including having access to effective psychological interventions such as DBT. When participants were able to access autism/ADHD pathways, although there were generally long waits for these, they felt supported and understood, particularly with regards to post-diagnostic workshops and support. By contrast, respondents felt that their personality disorder diagnoses often prevented access to effective therapeutic pathways and highlighted that the disorder excludes them from accessing NHS Talking Therapies for their symptoms of depression and anxiety.

## 3.3 Support and interventions

### *3.3.1 Post-diagnostic support*

Respondents felt that post-diagnostic support for both diagnoses was variable. Some highlighted the usefulness of a post-diagnostic information workshop following their autism diagnosis, whilst also emphasising a lack of longer-term support. No respondents felt that their personality disorder diagnosis had been properly explained to them. Furthermore, their personality disorder diagnosis had often led to an exclusion from services, rather than support. No respondents had received information about co-occurring autism/ADHD and personality disorder diagnoses. Many participants advocated for peer-led, educational support to help them understand their conditions, develop self-management skills and to provide information to their families and partners:

> *P2: "Well, I've just been left waiting now. I was given resources in terms of websites that I could read about. Just to do my own research about it. But otherwise, no, not really much in terms of support."*

### *3.3.2 Experience of therapies*

The majority of participants had accessed a psychological therapy for the treatment of BPD. Several respondents had received mentalisation-based therapy (MBT); dialectical behaviour therapy (DBT), which one respondent felt had helped them to build a positive self-identity; and cognitive behavioural therapy (CBT), which several participants felt had led to an increased understanding of emotions and coping skills for escalation of distress. Some reported positive experiences of these therapies being adapted to meet the needs of autism/ADHD. However, others felt that the therapy had not been accessible or helpful. Examples included being overwhelmed by the amount of information being provided, confusing use of abstract metaphors, and uncertainty about the techniques being learnt. All respondents felt that therapies required adaptations and adjustments to ensure engagement, positive experiences and improved outcomes:

> *P10: "I was doing DBT. That was really good for me, it helped so much teaching me how to use different techniques and finding out what I like myself as well […]. Other charts scale it (emotions) from 1 to 10 and I can't do that. So instead, we'd do like a happy face or a medium face or a sad face."*

### *3.3.3 Experience of groups*

Respondents had mixed views about group therapy for difficulties associated with personality disorder diagnoses. Positive experiences of groups included building a support network. However, difficulties included feeling like an outsider due to invalidation of their neurodivergent identity, and a lack of understanding of neurodivergence. Respondents also expressed sensory and social overwhelm, and had difficulties sharing in the group due to comparing themselves to others and trying to fit in. Some said that this increased their use of masking:

> *P9: "The whole experience was just massively invalidating and massively like I learned a lot about masking and became even better at masking and that made me even more unwell."*

Although the respondents had mixed views about whether neurodivergent only groups would be more helpful, the majority felt that adaptations such as shortening the length of the sessions and providing handouts and information in advance of the session would be helpful. They agreed that more work is needed to establish the effectiveness and optimal way of delivering group interventions for neurodivergent people.

#### *3.3.4 Feedback and evaluation of support*

This sub-theme focused on opportunities to provide feedback on support and interventions offered. Respondents understood the utility of outcome measures, but also felt that, for neurodivergent people, the questions were often ambiguous, and masking and camouflaging of symptoms limited the validity of these:

> *P4: "Sometimes when you do those, you're answering them, trying to get them right […]. There's no allowing for context as to when that question is asked […]. When it comes to masking, a questionnaire doesn't necessarily get to that."*

Respondents emphasised the importance of opportunities for providing feedback about their care in different ways, and that adaptations and adjustments were offered to ensure that they could participate. This linked to the theme of involvement and enablement, which was felt to be essential in reducing stigma and exclusion from services, and developing an effective pathway for neurodivergent people with personality disorder diagnoses.

### 3.4 Staff factors

#### *3.4.1 Understanding and skills*

Several respondents highlighted the importance of staff recognising autistic traits, such as difficulties with making eye contact and alexithymia, to help with identification of possible neurodivergence, help build trust and offering adjustments in communication and support. Whilst several respondents felt that training could help staff to recognise signs of autism and ADHD, they also recognised the complexity of identifying traits in neurodivergent people who mask or camouflage their symptoms, particularly in women who may present atypically, and highlighted the importance of individualised approaches:

> *P1:"We all mask to [a] degree but particularly the neurodivergent person a lot of them will be very good maskers. So, you might look for this set list of cues, but you'll see things, and you'll think that they have good eye contact, or they're dressed in a certain way or they're speaking like this and all articulate and stuff and they're not."*

Several respondents also spoke of the importance of staff having an understanding of their emotional and relational needs, and the ways in which they may be expressed, as well as how to respond helpfully to these:

> *P10: "…professionals didn't understand that, they saw everyone as just 'oh, you're just kicking off' or you're just like this naughty person' kind of thing and they wasn't too shy to say what they thought about you."*

#### *3.4.2 Staff attitudes and behaviours*

Respondents highlighted that some behaviours, such as self-harm, are associated with stigma. They gave examples of where they had perceived that clinicians had labelled and made assumptions about them, and that this had affected the clinicians' attitudes and behaviour towards them. Respondents emphasised the importance of holding curiosity about their individual needs and difficulties, rather than pre-determined narratives based on their diagnoses. They also described a 'double empathy gap' where both neurodivergent individuals and staff had difficulties communicating, understanding each other, and empathising with each other:

> *P1: "You should not create the narrative and create what you think this person is going to present with before you've even met them, before you've given them a chance to be. You need to give them that space to tell you what's going on for them and even look for cues as well."*

#### *3.4.3 Communication*

This sub-theme highlighted the importance of transparency and direct, effective communication, particularly regarding waiting times for referrals and in explaining decision-making. Respondents described acute distress associated with intolerance of uncertainty, and that this was exacerbated by lack of concrete information about waiting times and care planning. Respondents recognised the complexity of care planning and clinical pathways for neurodivergent people with personality disorder diagnoses, but felt that transparent, effective communication that was adapted for neurodivergent people was critical in mitigating distress associated with this.

Examples of good practice included providing written information in advance, breaking information down into small chunks, and avoiding ambiguous and abstract language. In addition, the importance of their views being listened to and validated in a compassionate way was also seen as helpful:

> *P1: "To just be given the opportunity to have a bit of a say maybe, or to understand decisions, and when things are just said and then you don't know why, you don't know the context and all that sort of thing. That's quite difficult. So, a bit more transparency I think it's needed."*

Some respondents highlighted the 'triple empathy' problem, where communication difficulties between autistic individuals and clinicians are exacerbated by a third layer of empathy breakdown—between patients, doctors, and the health care system itself. Suggestions for peer-led staff training and consistent adoption of neuro-inclusion passports were made.

#### *3.4.4 Therapeutic relationship*

The importance of trusting therapeutic relationships with staff in mental health services was emphasised. Both compassion and empathy were consistently mentioned by respondents as key elements to the therapeutic relationship, to increase the likelihood of successful engagement and reducing iatrogenic harm. Trust was mentioned several times, and the challenges of building trust when clinicians held negative labels and assumptions, and where attempts to engage with services had been unsuccessful or a clinical pathway had not been offered. Trust was discussed both in the context of individual relationships, and with services as a whole:

> *P4: "There's a lot of shame attached to unrecognised autistic experiences. So, helping someone to think about that again, that's the compassion focused area [...]. Taking that blame away was really, really helpful."*

## 3.5 Involving and enabling

### *3.5.1 Adaptations and adjustments*

Respondents highlighted the importance of adaptations to address sensory needs, for example, having adjustable lighting, fidget toys and reduced visual/auditory noise in the physical environment. Changes to group and individual therapies were also suggested, such as use of visual learning, allowing longer processing time and breaking down information into smaller pieces. Reducing uncertainty was a key adaptation; respondents suggested this could be achieved by providing information in advance, ensuring consistency and having clearer communication:

> *P3: "And [she] makes sure I got fidget toys, and I have ear things and make sure that I put them in if need be. And she does visual stuff with me as well on the board that I can understand. And she explains things, she doesn't give up on me put it that way, she will find other ways to try and explain something to me."*

### *3.5.2 Person-centered*

This sub-theme focused on improving person-centered, collaborative approaches in care-planning and decision-making. It draws on previous themes of adapting communication and improving staff understanding of the needs of neurodivergent people, as well as developing more integrated and joined-up pathways so that the individual is at the heart of their care. Service-level challenges of resources, time and service design were recognised and acknowledged. However, respondents also highlighted the effectiveness and value of greater service-user involvement and peer-led support and suggested that there be opportunities for individuals with both autism and/or ADHD and personality disorder to be involved in delivering services and supporting their peers. In addition, although greater understanding of both diagnoses was felt to be essential, respondents balanced this with ensuring that the needs and views of the individual were prioritised:

> *P1: "I think it's just showing a bit of respect for the person that's in front of you and just trying to hear them and create that safe space for them to feel that they are heard."*

### *3.5.3 Involvement and empowerment*

Building on the previous sub-theme of person-centered care, respondents said that they wanted to be more involved in their care and in shaping services. Several described positive experiences of co-production and involvement, however, others said that opportunities to give feedback were limited. Some felt that staff perceived them as 'difficult' and that this made it harder for them to give feedback about their experiences. In addition, they highlighted that there were limited methods to give feedback, and these methods were not adapted for the needs of neurodiverse people, both in terms of the language used, and lack of sensitivity for their experiences and concerns:

> *P1: "I think that's another thing that's lacking in a lot of different aspects of services as well that you're not asked. You're just told stuff even, and if you don't agree, then it doesn't matter. Or if you want to challenge it, you can't."*

## 4 Discussion

This study explored the perspectives of ten neurodivergent women with a personality disorder diagnosis on clinical pathways in community mental health services, using reflexive thematic analysis. Respondents identified components of this pathway, such as identification and assessment of individual needs; support and interventions provided; staff understanding and attitudes; transitions between services; and involvement and enablement. They described their experiences of seeking support and gave their perspectives on optimal pathways for people with these co-occurring diagnoses. Their views will inform the design and evaluation of a pilot clinical pathway for neurodivergent people with personality disorder diagnoses in an NHS Mental Health Foundation Trust within the South-East of England.

The findings of this study and from wider literature highlight the complexity of identifying autism and ADHD in adults with a diagnosis of personality disorder, due to overlapping traits [35, 47], lack of specificity of screening measures within a clinical population, and high face-validity of these measures [10]. In addition, there are still high levels of stigma associated with a personality disorder diagnosis [48, 49], and it remains a diagnosis of exclusion to NHS Talking Therapies Services [50]. As a result, where there is diagnostic uncertainty, both staff and patients increasingly prefer autism as a diagnostic label [51]. However, where both may co-occur, this risks excluding individuals from accessing evidence-based and effective psychological therapies for personality disorder [4, 52]. It also impedes the development and evaluation of new and adapted psychological interventions for this population. The study therefore highlights the importance of designing and implementing a bespoke pathway for individuals with co-occurring needs, which is person-centered, needs-based and formulation-driven.

### 4.1 Clinical implications

Participants highlighted that recognition of neurodivergence can reduce stigma, increase validation, and can lead to reasonable adjustments and support across settings, including education and the workplace [53]. The opposite is often true for personality disorders, where individuals may experience negative labelling and assumptions from staff [48] and may experience structural exclusion from NHS Talking Therapies services based on their diagnosis [54, 55]. Some participants rejected a personality disorder label and felt that personality disorder should not be given as a co-occurring diagnosis for autistic people. However, others felt that this was a helpful and validating way of conceptualising their difficulties although highlighted risks of structural stigma and exclusion from mental health services for both diagnoses [56]. They felt further work is needed to reduce stigma associated with personality disorder amongst mental health professionals and highlighted this as a training need to improve knowledge, skills, and changing attitudes [28, 50]. Furthermore, post-diagnostic support, and clear pathways were seen as essential post-diagnosis for both conditions.

The participants varied on whether they identified with the personality disorder diagnosis, although they all identified with autism and/or ADHD. There was an emphasis on the importance of training on the identification of autism/ADHD, and how these may interact with each other, as well as with personality disorder. They also highlighted training to help with understanding masking; the social and emotional impact of both diagnoses; and the importance of reducing structural stigma within mental health services [6]. Brief training about personality disorder has been successfully delivered for frontline mental health staff. It has been shown to lead to sustained improvements in knowledge, skills, confidence and attitudes towards people with a personality disorder diagnosis [57], although other recent research suggests that training may in some cases lead to increased stigma by clinicians [58]. Embedding experts by experience into the design and delivery of the training was seen to be essential, as was taking an intersectional approach within training.

A major finding was that many participants felt that diagnostic assessments often led to diagnostic overshadowing, and often did not lead to accurate identification of either neurodiversity or difficulties associated with personality disorder, particularly in non-specialist community mental health services [35]. This is consistent with wider research that highlights the overlapping features shared across these conditions [47]. Consistent with the literature about the lack of sensitivity and specificity of screening measures to differentiate these diagnoses within clinical settings, findings from this study highlight the need for an integrated, formulation-driven screening and assessment process [30].

Formulation is crucial to identifying individual needs in relation to neurodivergent and mental health aspects and enabling decisions about interventions and adjustments [27]. It should also include an autism-adapted safety planning tool [59]. The assessment would then lead to a modular pathway which is tailored to a person's needs and may include an enhanced neuro-inclusion passport which informs adjustments and adapted communication and support. This would also allow access to peer-led support, which provides self-management tools, validation and exploration of the emotional and social impact of their difficulties.

Research suggests that inclusion and communication passports improve empowerment and engagement [60], healthcare outcomes [61] and retention in services, although further research into the optimal design and implementation of neuro-inclusion passports is needed. Whilst neuro-inclusion passports have promise, the respondents recommended that these are enhanced for people with a personality disorder diagnosis, and design and testing of an enhanced neuro-inclusion passport is a priority [28]. It is possible that the effective use of these will make it more likely that this group access services that meet their needs, reducing iatrogenic harm and improving trust in services [62].

Similarly, participants also felt that peer-led psychoeducation was important, to explore the social and emotional impact of diagnosis, support with the development of self-management and safety-planning tools and reduce the triple empathy gap between individuals, professionals and services [27]. Peer-led interventions have been successfully adopted within specialist neurodevelopmental services [22]. However, there has been limited application of this approach within community mental health services, and the effectiveness and optimal approach to peer-led self-management and support interventions in such settings is lacking [63].

The pathway may also include access to individual and group therapies for personality disorders, such as Dialectial Behaviour Therapy (DBT), Mentalisation Based Therapy (MBT) or Cognitive Behaviour Therapy (CBT). However, participants highlighted the importance of adapting these, both in terms of delivery as well as the content. Overall, participants felt that pathways through services should be integrated and individualised, as an alternative to siloed pathways and ways of working.

## 5 Research implications

This was a small-scale qualitative study that was carried out as part of a quality improvement project to explore experiences of clinical pathways, and recommendations for improvement.

Further research is needed to determine the generalisability of these findings. Such research could explore the experiences of other gender identities and ethnicities, as well as investigating differences in experiences between autistic and ADHD individuals who have been diagnosed with personality disorder. Research into the experiences of those who have self-identify as autistic or having ADHD, compared to those who have received these diagnostic labels, would provide information about whether self-identification impacts their perspectives on services [36, 37]. It is also possible that overlapping features such as emotion dysregulation and mentalisation difficulties could be the basis for the development of needs-based, transdiagnostic therapy models that target the overlapping features of autism/ADHD and personality disorder [47].

The findings of this study, together with research evidence and best-practice guidelines, will be used to design and pilot an integrated clinical pathway within an NHS Mental Health Trust. Findings support the development of a modular pathway with components that include an integrated screening template, peer-led support, adapted therapies, and a staff training programme which has levels of training tailored to the role of the staff member. Evidence for the effectiveness of indirect interventions such as implementing reasonable adjustments and neuro-inclusion passports is lacking, and the impact of these can be difficult to measure. Therefore, the development and evaluation of these components of the pathway will be a research priority.

Further, the outcomes that are important to service users are unclear, and perceptions of quality of life may be different for neurodivergent people [64]. Therefore, the development of measures that have been adapted for this population will also be important, to ensure that interventions lead to meaningful outcomes and support future research into the acceptability and preliminary effectiveness of these components. Evaluating the clinical and cost-effectiveness of the pathway as a whole is a priority, to improve access and outcomes for neurodivergent individuals with personality disorder diagnoses [18, 65, 66].

### 5.1 Strengths and limitations

Our sample size of ten participants provided sufficient information power to elicit rich data and is consistent with sample sizes of similar studies [33, 51]. Participants who volunteered for the study all identified as female and therefore may limit generalisability of findings to other gender identities. However, this female participant group is representative of the high proportion of women diagnosed with EUPD. Therefore, the study provides important perspectives of a vulnerable and often marginalised patient group [68].

The study was co-designed in partnership with the Trust's Reasonable Adjustments Service (RAS), and one of the members of the study team, and co-author, is a neurodivergent woman with personality disorder diagnoses, who has experience of accessing mental health services. The data-collection process was co-designed and piloted with experts by experience and designed to be accessible for neurodivergent people, with reasonable adjustments implemented. Respondents were involved in the design and reviewing of themes. Their perspectives are then being used to co-produce a clinical pathway, and they will be involved in futures service improvement work. This participatory and truly co-produced approach is expected to significantly improve the quality and effectiveness of service design.

The demographics of this sample (white British) were reflective of the local population for which the pathway will serve, but did not represent the diverse characteristics of different communities within the UK. Therefore, further research is needed to explore the experiences of other communities on accessing mental health services in order to understand the generalisability of the findings to other communities. Specifically, there is a lack of evidence about the demographic factors which lead to diagnostic overshadowing or misdiagnosis of autism and thereby influence their experience of services [67]. Purposive and snowball sampling within a single NHS Trust risks excluding those with the most challenging and negative experiences of services, as volunteers for service improvement methodologies are motivated to engage in participation and may not be representative of this group [68].

For the purposes of this study, autism and ADHD were both included. However, there could be differences in experiences between these two groups, although the high prevalence of co-occurring autism and ADHD is also acknowledged [40, 69]. Amongst the respondents, three identified with both neurodivergent and personality diagnoses, whereas seven identified just with their autism/ADHD diagnoses, and did not feel that their personality diagnosis was helpful or accurate. This latter group may have had different experiences of clinical pathways, and different perspectives on support offered. This was not explicitly explored within the study, although we did describe a range of perspectives within the themes.

### 5.2 Conclusion

This study explored the views of neurodivergent women with a personality disorder diagnosis, on their experiences of seeking support from mental health services, and recommendations for an optimal clinical pathway. The findings highlighted that both diagnoses can be exclusionary, and that diagnostic overshadowing is common. The study highlights the importance of an integrated, person-centered and needs-based pathway that is tailored for this population. Findings from the current study will inform the design and testing of an integrated clinical pathway within a NHS Mental Health Foundation Trust, and future research to evaluate the effectiveness and generalisability of the pathway [66].

Findings suggest that the pathway should be modular, with support offered based on the needs of the individual. Components of this may include an integrated screening measure and enhanced neuro-inclusion passport that identifies reasonable adjustments, as well as peer-led support and psychological therapies. The continued involvement of experts by experience, as well as frontline staff, service leaders and other stakeholders, will be essential in the development of effective pathways for neurodivergent people with personality diagnoses, who seek support from mental health services.

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1007/s44192-025-00340-0.

Supplementary Material 1

**Acknowledgements**

The authors thank Bernie Ennis, Imogen Hanvey, Robyn Darby and Simon Tarrant for their support in co-producing the topic guide of questions and assisting with reasonable adjustments. We thank David Brind for his help in transcribing the data. The authors thank the Oxford Health Quality Improvement Hub, Elizabeth Cook for all her support. We thank the participants for their contributions and involvement.

### Author contributions

RG developed the proposal for the project, carried out data collection, transcribed and analysed data, and co-wrote the paper. ZM developed the proposal for the project, carried out data collection, and co-wrote the paper. CCR developed the proposal for the project, advised on data analysis, co-wrote the paper and supervised the project. HC carried out data collection and reviewed a draft of the manuscript. TD carried out data collection and reviewed a draft of the manuscript. JP reviewed a draft of the manuscript.

**Funding**

The authors did not receive support from any organization for the submitted work.

### Data availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## Declarations

### Ethics approval consent to participate

This analysis is part of a project registered at Oxford Health NHS Foundation Trust (OHFT) as Quality Improvement (Developing A Pathway For Neurodivergent Adults With Complex Needs In Primary Care Mental Health). As such, it does not fall under the Health Research Authority's definition of clinical research and has not required a submission for ethical review. However, OHFT can confirm that the project has been conducted in accordance with all relevant policies and procedures and is happy that due ethical consideration has been given. OHFT would support submission of the manuscript for publication. Written informed consent was obtained for participation in this study.

### Consent to publish

Written informed consent was obtained for anonymised patient information to be published in this article.

### Competing interests

The authors declare no competing interests.

Received: 2 May 2025 / Accepted: 12 November 2025

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## Publisher's note