### ORIGINAL ARTICLE

**IARID** 

# 'It's working together with what you've got': Healthcare professionals' experiences of working with people with combined intellectual disability and personality disorder diagnoses

Nicolò Zarotti<sup>1</sup> | Clive Hudson<sup>2</sup> | Hannah-Rose Human<sup>2</sup> | Greco Muratori<sup>3</sup> | Paul Fisher<sup>1</sup>

<sup>1</sup>Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, Norwich, UK

<sup>2</sup>Adult Community Learning Disability Service, Suffolk, Norfolk and Suffolk NHS Foundation Trust. Lowestoft. UK

<sup>3</sup>Adult Community Mental Health Service, Norfolk and Suffolk NHS Foundation Trust. Norwich, UK

#### Correspondence

Nicolò Zarotti, Department of Clinical Psychology and Psychological Therapies (CPPT), Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich NR4 7TJ. UK.

Email: n.zarotti@uea.ac.uk

### Abstract

Background: People with intellectual disability often receive diagnoses which may complicate their clinical care. Among these, personality disorder diagnoses are still considered contentious. Little is also known on the perspectives of staff caring for people with intellectual disability who have received a personality disorder diagnosis.

Methods: Three focus groups were carried out to explore 15 healthcare professionals' subjective experiences of working with people with intellectual disability who also have a recorded additional diagnosis of personality disorder. Data were analysed through thematic analysis.

Findings: Four overarching themes were identified: (a) diagnostic issues and the need for person-centred approaches; (b) challenges and adjustments to working with combined intellectual disability and PD diagnoses; (c) the importance of multidisciplinary team training, support, and cohesion; (d) provision issues and barriers to service access.

Conclusions: The themes are outlined in depth and a number of implications for clinical management and service improvement are discussed.

#### KEYWORDS

diagnosis, healthcare professionals, intellectual disability, personality disorder, qualitative

#### INTRODUCTION 1

Mental health difficulties are estimated to be three to four times more frequent among people with intellectual disabilities (Cooper & Van Der Speck, 2009). As a consequence, people with intellectual disability often receive a number of diagnoses which may complicate the

formulation, planning, and management of the most appropriate care for their needs (Carr et al., 2016). One of the most contentious is the diagnosis of a personality disorder (PD), defined as a condition where adult individuals present a number of 'enduring personal characteristics (personality traits) that significantly impair their well-being and social functioning' (Webb, 2014, p. 8). While interest in PD has

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. © 2022 The Authors. Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.

1318 WILEY\_ARID

increased over the past decade (Lee & Kiemle, 2015), this has not reflected in the adult intellectual disability population (Torr, 2003), in which emotional difficulties and well-being have, in earlier periods, been somewhat overlooked (Arthur, 2003). In addition, the validity of PD diagnoses in general as well as in people with intellectual disability has often been under scrutiny due to concerns regarding stigmatisation, clinical utility, and appropriateness (Milinkovic & Tiliopoulos, 2020; Webb, 2014). More recently, this debate has prompted the development of a new PD model for the ICD-11, which represents a paradigm shift which 'moves from an unnecessarily complicated classification system, most categories of which were never used, to a simpler, more evidence-based model' (Mulder, 2021; p. 4).

However, it has also been suggested that individuals with intellectual disability may be at higher risk of developing a presentation diagnosed or labelled as PD due to delayed or incomplete development and increased early exposure to adverse events (Flynn et al., 2002; Pridding & Procter, 2008). All these factors, along with the limited availability of adequate assessment tools (Moreland et al., 2008), may also partly explain the extremely variable prevalence rates that have been reported so far for PD diagnoses in this specific populationranging from 1% to 91% in community settings and 22%-92% in hospitals (Alexander & Cooray, 2003).

The current knowledge on the impact of PD diagnoses in people with intellectual disability remains guite scarce, with most of the research to date focusing predominantly on epidemiology and prevalence rates (Flynn et al., 2002), especially within forensic settings (Alexander et al., 2012; Rayner et al., 2015). The qualitative literature around this topic appears to be even sparser, with little to no insight currently available on the subjective experience of healthcare professionals (HCPs) working with these presentations. In particular, only one qualitative study to date has investigated the perspectives of qualified nurses, again in a forensic setting, highlighting the complexity of daily clinical work, staff's ambivalence towards PD diagnoses, and the importance for knowledge, training, and resilience (Lee & Kiemle, 2015).

This article presents the results of a service evaluation which used gualitative focus groups to explore the subjective experience of HCPs working with individuals with intellectual disability and PD diagnoses in the east of England. This was part of a larger initiative promoted by the host National Health Service (NHS) Trust and aimed at gaining insight into the issues associated with these presentations within a community setting, with the potential to inform changes to clinical care pathways and service provision.

#### 2 **METHODS**

#### 2.1 Methodological approach

This project adopted a qualitative approach (Cresswell, 2007). Semistructured interviews were used to conduct three focus groups (FGs) with specialist adult intellectual disability HCPs in NHS community adult intellectual disability services across the area of East Anglia (UK).

#### TABLE 1 Summary of the FG participants by profession

Profession	FG1	FG2	FG3
Community nurse	1	2	3
Charge nurse		1	
Psychiatrist	1		
Community team manager	1		
Speech and language therapist	1		
Assistant psychologist	1		
Clinical psychologist			2
Clinical support worker		1	
Occupational therapist			1

Abbreviation: FG, focus group.

#### 2.2 Sampling and recruitment

Convenience sampling was used, whereby HCPs from East Anglia working clinically in intellectual disability services were invited to participate. In order to maximise the diversity of experiences within each FG, all professional figures and job roles involved with this population were considered eligible.

#### 2.3 **Participants**

A total of 15 HCPs from five specialist multidisciplinary teams (MDTs) took part in the three FGs. The participants represented nine job roleswith Community Nurse being the most frequent (N = 6; 40%)—and were predominantly female (N = 11, 73.3%). Table 1 summarises the participants by profession and the composition of each focus group.

#### 2.4 Procedure

All FGs were conducted online in mid-2021 via Microsoft Teams<sup>®</sup>, lasting 60 min on average (range: 55-66 min) and involving four to six participants each. The interview schedule was structured into five main topics to provide a general framework for the discussion (see Table 2). These were agreed through iterative discussions and consultations between the project team members, and included: (a) Service/team context introduction and description; (b) Personal experiences of working with people with combined intellectual disability and PD diagnoses; (c) Benefits and disadvantages of diagnosing PD within the context of intellectual disability; (d) Barriers and enablers to diagnosis and management of combined intellectual disability and PD diagnosis; (e) Closing remarks.

#### 2.5 Data analysis

Each FG was digitally audio-recorded and transcribed verbatim. The resulting data were then imported into the NVivo® software and analysed thematically according to the principles outlined by Braun

# **TABLE 2** Summary of the five main topics of the interview schedule

Торіс	Example question
Service/team context introduction and description	Can you please describe briefly your intellectual disability service/ team?
Personal experiences of working with people with combined intellectual disability and PD diagnoses	How would you describe your experience of people with intellectual disability that have been associated with a diagnosis of PD?
Benefits and disadvantages of diagnosing PD within the context of intellectual disability	Do you believe there are any benefits to making a PD diagnosis in people with intellectual disability?
Barriers and enablers to diagnosis and management of combined intellectual disability and PD diagnoses	What are the main challenges when diagnosing a PD in a person with intellectual disability?
Closing remarks	Is there anything else that you would like to say that you have not had the opportunity to say yet?

Abbreviation: PD, personality disorder.

and Clarke (2006, 2012). Thematic analysis (TA) was considered appropriate due to the exploratory nature of the project and since it allowed for both a deductive and inductive approach to the themes emerging from the transcripts (Harper & Thompson, 2011). A critical realist epistemological stance was assumed throughout, whereby people's experiences were recognised as equally real and meaningful as physical and behavioural phenomena (Sayer, 2000).

The analysis began with a data familiarisation session consisting of multiple readings of the transcripts and the identification of initial ideas. Then, initial codes relevant to the project aims were identified and linked to preliminary themes that had emerged across the entire dataset. A review of the initial themes was then performed to ensure consistency with the codes (Level 1) as well as the whole dataset (Level 2). After this, clear names and definitions for each specific theme and a thematic map were collectively generated and checked against the data by another member of the team. Finally, a report of the overall findings including a selection of the most representative quotes was drafted by the first author and checked independently for consistency by two further team members. These steps were followed carefully to ensure that the criteria for rigour and trustworthiness in TA (e.g., transparency, credibility, reliability; Nowell et al., 2017) were met.

### 2.6 | Ethical considerations

Formal approval and registration of the service evaluation was granted by the Research and Development Department of the host NHS Foundation Trust (Ref: 2021MH22-SE). Written informed consent was obtained from all participants.

#### **TABLE 3** Summary of the identified themes and relative codes

ARID

Theme	Codes
1. 'It's knowing the person as well': diagnostic issues and the need for person-centred approaches	Diversity of presentations
	Person-centred approach
	Pros and cons of diagnosing
	Traits vs. diagnosis
<ol> <li>'You've got to try to put up boundaries': challenges and adjustments to working with people with combined intellectual disability and PD diagnoses</li> </ol>	Communication and social difficulties
	Dependency and boundaries
	Increased risk and vulnerability
	Management and discharge issues
3. 'I think it's talking to your colleagues,	Lack of key staff
isn't it?': the importance of MDT training, support, and cohesion	Lack of training and confidence
	Need for MDT cohesion
<ol> <li>'Unfortunately, a diagnosis also means a service': provision issues and barriers to service access</li> </ol>	Diagnostic overshadowing and gatekeeping
	Importance of inter- service liaison
	Low wages and resources
	Need for guidance and supervision

Abbreviations: MDT, multidisciplinary team; PD, personality disorder.

#### 3 | RESULTS

#### 3.1 | Overview of identified themes and codes

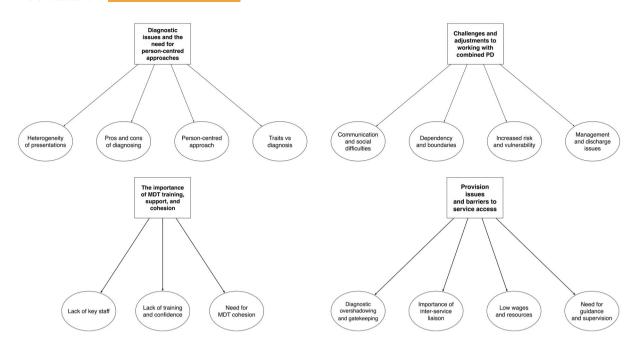
Initially, a preliminary list of 36 codes was generated. Following Review Level 1 and 2, 15 final codes were identified and organised into four overarching themes. Table 3 provides a summary of the main themes and respective codes, while Figure 1 illustrates the final thematic map. The findings of the project are outlined below, along with specific quotes labelled according to the FG they belonged to.<sup>1</sup> The names of specific codes are highlighted in italics within the text.

## 3.2 | Theme 1: 'It's knowing the person as well'— Diagnostic issues and the need for person-centred approaches

The first theme to emerge from the FGs revolved around the process of people with an intellectual disability receiving a PD

<sup>&</sup>lt;sup>1</sup>To avoid confusion, the term 'learning disability', more commonly used across services in the United Kingdom, has been replaced in the quotes with 'intellectual disability'.

1320 WILEY-JARID





diagnosis. Many HCPs highlighted how difficult it can be to provide a diagnosis of PD due to the *diversity of presentations* which characterises this population, including issues around overlapping symptom presentations and reduced engagement with the assessment process:

I find it very difficult to make the diagnosis of personality disorder in people with intellectual disability, because of the overlap of signs and symptoms.—FG 1

It's just so difficult to diagnose people with an intellectual disability by virtue of their intellectual disability and their inability to engage in an assessment or a diagnostic process.—FG 3

HCPs also reported that people with intellectual disability may frequently show a number of personality *traits* linked to PD rather than meeting all the diagnostic criteria:

I haven't worked with many people who've had maybe a formal diagnosis of personality disorder, but people will refer to 'traits'.-FG 2

I can't personally think up a case where there's a clear PD diagnosis that's been given. We talk an awful lot, certainly in our team, about personality traits.—FG 3

Combined with the abovementioned issues around symptom overlaps, this was perceived to add a further layer of complexity to the assessment process: Definitely diagnosis of personality disorder happens more rarely. And once it happens, then the next step is even more difficult. (...) Because of their sort of complex issues.-FG 1

Further, many HCPs felt that their own assumptions around PD and the potential *pros and cons of diagnosing* had a significant impact on assessments, especially due to the perceived risk of stigmatisation:

There might be a bit of a stigma, not necessarily from our team but maybe other services, and maybe family members and friends.—FG 1

When we've queried PD, there's a bit of resistance in regards to assessment, perhaps 'cause there's still quite a... taboo'.—FG 3  $\,$ 

To some participants diagnosing PD was perceived as adding a further stigmatising label to a population, which already struggled with lots of stigma, which may in turn affect the service they receive:

> Maybe there's a reluctance because of the sort of stigma that's still attached. Because we're used to working with people who've been stigmatised their whole life, and they're incredibly vulnerable to those kinds of negative attitudes.—FG 3

> Recently I've had a lady who (...) has suspected emotionally unstable personality disorder and the social worker sort of said that she struggles working with people with personality

disorders. (...) So, I do feel like her having that label has meant that she's not getting as much of a service as she should.—FG 1  $\,$ 

By contrast, others thought that a clear diagnosis may at times be seen as receiving long-sought explanations for an individual's difficulties, and might in fact help improve understanding and support for service users and their families:

> It might be useful for the person to understand their own difficulties, if you can explain to them what that means. And I worked for somebody for a number of years where that was the case.—FG 1

> We a lot of young people whose families or carers seek out those extra diagnoses. Looking for answers, I think.— FG 2

Irrespective of their assumptions, the majority of HCPs agreed that the assessment of people with intellectual disability required a *person-centred approach*, which focused on presentations and narratives rather than diagnoses:

As an MDT, we look at the presentation and work out the best way to approach it.—FG 1  $\,$ 

I think it's fair to say that our approach is very individual, based on who we're working with rather than based on a diagnosis.—FG 3

This was perceived not only as a way to get to know service users better, but most importantly as a means to avoid defining them by their diagnoses and see them as individuals with a story:

We as a service, you know, we do focus on the individual and try not to define somebody by their diagnoses.—FG 2

Every individual is different. (...) It's knowing the person as well.—FG 2

However, when a person with an intellectual disability did receive a PD diagnosis, it usually meant they presented with a significant number of additional clinical challenges.

## 3.3 | Theme 2: 'You've got to try to put up boundaries'—Challenges and adjustments to working with people with combined intellectual disability and PD diagnoses

The clinical management of individuals with intellectual disability and PD diagnoses was perceived by most HCPs to be especially challenging. This appeared to reflect on all levels of clinical work, starting with fundamental *communication difficulties*, which affected information gathering and rapport building with service users:

The case I was speaking about earlier, this sort of query diagnosis of borderline PD... there were real difficulties in both giving and kind of getting information from the individual.—FG 1

Another thing they often seem to do is 'splitting'. Saying one thing to one professional, and another to someone else.—FG 3  $\,$ 

In the case of people with milder intellectual disability and a PD diagnosis, *social difficulties* were also thought to have a significant impact, particularly as they could be subtler than other issues whilst still affecting availability of care:

We find that a lot of people with milder intellectual disability... (...) because they can do a certain amount of things independently, like personal care, cook and clean for themselves, they don't actually get allocated much support from social care. But they also have an absence of friends and family in their lives.—FG 2

Often, the combination of these problems was also felt to lead some service users with PD diagnoses to develop a *dependency* on specific professionals or services:

I think that's why the few people I've worked with have made attachments to professionals.—FG 2

They'll call up and just say my carers haven't turned up, sort it out [laughs]. (...) Even with numerous amounts of support, (...) there's still that dependency to come back to services to fix things.—FG 3

For some HCPs, this dependency appeared to be in part due to attachment seeking behaviours which led service users to develop very strong relationships with staff. In turn, this encouraged HCPs to feel the need for making adjustments to their clinical approach, such as setting very clear *boundaries* to provide the appropriate amount of support while also preventing service users from becoming dependent on them or the service:

They'd form such relationships, over such a length of time... and become quite dependent on those relationships, of which obviously professionals have to be very careful.—FG 2

You've got to try to put up boundaries, that's the key to it as well, isn't it?—FG 3

1322 WILEY\_ARID

Dependency in people with both intellectual disability and PD diagnoses was also thought to cause a number of long-standing clinical management issues, particularly around discharge:

> If you sort of mention discharge, then they may think that they have to do something or say something, meaning that they end up staying with the service.-FG<sub>1</sub>

> In the time that I've been with the Trust, typically they have been people that, because of those associated challenges, are very hard to move on from the (...) unit.—FG 2

Ultimately, many HCPs felt that these attachment seeking presentations often led to increased risk and vulnerability both for themselves and service users:

> I had a young lady that was open to me (...) she did have [PD] diagnosis... but there were a lot of management issues, managing her care. (...) A very risky situation at times.—FG 1

> You can be quite vulnerable as a professional, can't you? When you're working with somebody with a personality disorder.-FG 3

Some HCPs also thought that risk management had to be adjusted in the form of shared positive risk taking, whereby they would take a calculated risk as a team to refrain from feeding back into some service users' dependency:

> Sometimes that involves positive risk taking, such as not picking up the phone immediately and calling them back if they left me a really horrible voicemail where they're blaming me for absolutely everything.—FG 3

Notably, the successful implementation of MDT work was seen by the participants an essential way to tackle these multi-faceted clinical challenges.

#### 3.4 Theme 3: 'I think it's talking to your colleagues, isn't it?'-The importance of MDT training, support, and cohesion

The importance of being part of a supportive MDT was highlighted as vital by the vast majority of HCPs. In particular, the need for MDT cohesion was especially felt, as lack of consensus among professionals was seen as quite challenging for the team:

> I think that in the behind-the-scenes care, that MDT working, (...) those conversations and emails and things, they were quite tense sometimes, because of the

conflicting opinions. I think the lack of consensus caused a lot of problems.—FG 1

By contrast, open dialogue was seen as important because it allowed for the sharing of information and specialist knowledge around intellectual disability which could facilitate positive outcomes during everyday clinical work:

> The kind of wonderful MDT working that you often get in intellectual disabilities teams. I think that you often have a wealth of knowledge.—FG 2

> I think it's talking to your colleagues, isn't it? That's the most important thing. Talking to your colleagues about the problems that you're encountering.-FG 3

However, HCPs across all FGs also perceived a significant lack of training and confidence when it came to working with people presenting with PD traits or diagnoses within the context of intellectual disability, particularly due to how challenging these mixed presentations can be:

> I've had, basic training on personality disorders, but never any sort of specialised training, in regards to people with personality disorder and intellectual disability.-FG 1 Something like a personality disorder, you have to have a real understanding of that.—FG 2

In addition, some HCPs believed that their ability to work with people with both intellectual disability and PD diagnoses had been considerably limited by the lack of key staff within the MDT who may be confident or trained in providing a PD diagnosis:

> We don't have a psychologist in our team at the moment. (...) Our psychologist would mainly be doing things like autism assessments. (...) I can't remember him doing any PD work.-FG 2

> We've gone through lengthy periods without having psychiatry. (...) And when we do have psychiatry, we're very dependent upon that individual psychiatrist and their training and their confidence.—FG 3

Far from being only linked their specific MDTs, these limitations were also felt to be a reflection of wider problems at the service provision level.

#### 3.5 Theme 4. 'Unfortunately, a diagnosis also means a service'-Provision issues and barriers to service access

A number of significant issues around services' ability to provide appropriate care for people with both intellectual disability and a PD

diagnosis—as well as service users' ability to access it—were highlighted by the majority of HCPs. For instance, a common problem was represented by *diagnostic overshadowing*, whereby many facets of presentations of people with intellectual disability tend to be seen predominantly through the lens of their intellectual disability diagnosis. This can in turn exert a *gatekeeping* effect to accessing more appropriate alternative services:

> When it comes to PD, that is almost... if anything, overshadowed by the intellectual disability.—FG 3

There's also, in an awful lot of cases, a good deal of diagnostic overshadowing. People will behave in a way that services find challenging, and that behaviour will be attributed to their intellectual disability rather than anything else. If you already got an intellectual disability diagnosis, then your chances of getting someone into a specialist PD service immediately go through the floor.— FG 2

For many HCPs, such a tendency was linked to the *importance of inter-service liaison*, and the harmful impact that friction between services may have on patients' care:

When we go to the adult pathway, the crisis team, they're like, 'well, you're under the intellectual disability team', so, 'no-thank-you' sort of attitude, which is not helpful.—FG 3

Unfortunately, a diagnosis also means a service, at times, doesn't it? When somebody has an intellectual disability, that (...) seems to be the primary diagnosis.—FG 2

In particular, this was perceived to be in direct contrast with the ideal situation of seeing people with intellectual disability being granted easy access to mainstream mental health services:

It [should be] sort of a no closed doors approach (...). If you've got a mild intellectual disability, you should have access to generic services, which on paper looks absolutely spot on.—FG 3

HCPs also felt they had a strong *need for guidance and supervi*sion when working with people with intellectual disability and PD diagnoses, particularly concerning professional and emotional support:

That clinical supervision too, which is absolutely vital, when you're working with someone with those really complex presentations.—FG 2

I think maybe, like emotional support for staff. (...) Sometimes people with a personality disorder can tie you up in knots and can press your buttons.—FG 3 However, it was also recognised that part of the provision issues in some services might be explained by *low wages and resources*, which may in turn lead some HCPs to leave their employment:

For the staff teams themselves, if they can make more money bleeping groceries at Aldi, than working with someone who might physically assault them... (...) why wouldn't you?—FG 2

It's around that recruiting and training the right people. People don't stay with a single provider for long. (...) They will go where they can get an extra four quid an hour. And I think, as a result services are leery of investing in their staff team.— FG 2

### 4 | DISCUSSION

This article explored the subjective experience of HCPs working with people with intellectual disability who subsequently receive a PD diagnosis. Three FGs were carried out with a total of 15 HCPs representing nine job roles across NHS community adult intellectual disability services in East Anglia (UK). Four overarching themes emerged from the data: (a) diagnostic issues and the need for person-centred approaches; (b) challenges and adjustments to working with people with combined intellectual disability and PD diagnoses; (c) the importance of MDT training, support, and cohesion; (d) provision issues and barriers to service access. To our knowledge, this is the first qualitative evaluation investigating the perspectives of a wide range of community-based professionals around this specific population.

The first theme concerned the issues associated with giving a diagnosis of PD to people living with an intellectual disability, which included highly diverse clinical presentations, symptom overlap, HCPs' ambivalent assumptions around PD (e.g., stigmatisation, explanatory value), and the perceived presence of only certain PD traits as opposed to a full PD diagnosis. All of these appear to be consistent with much of the critique around the validity of PD diagnoses in this setting (Lee & Kiemle, 2015; Moreland et al., 2008). Partly as a consequence of these complexities, most HCPs also felt that a personcentred approach was the most appropriate way of carrying out assessments, particularly as it allowed staff to validate service users and see them as individuals rather than labels. This was perhaps not surprising, considering the long tradition of successfully adopting individualised ways of working with people with intellectual disability, including person-centred thinking, planning, and active support, as well as narrative approaches (Carr et al., 2016). In this regard, formulation-based approaches have often proved to be critical in making sense of the multiple layers of complexity that the presentations of people with intellectual disability and PD diagnoses entail, as well as in providing validation to the experience of service users (Carr et al., 2016; Kramer, 2019).

When people with an intellectual disability did present in a way considered consistent with a PD diagnosis, HCPs felt that such

1324 WILEY\_JARID

presentations carried a considerable number of additional challenges in everyday clinical work. These challenges formed the core of theme two, which outlined issues such as communication and social problems, difficulties building meaningful clinical relationships, and increased risk and vulnerability for both HCPs and service users. Many participants felt they had to make extra adjustments to overcome these specific challenges, such as sharing positive risk taking with the MDT or establishing solid boundaries to avoid dependency on services or problematic attachment seeking while still providing appropriate care and dealing with difficult discharges. Such issues were consistent with previous quantitative descriptions available in the literature (Torr, 2003; Webb, 2014), and especially with the only other qualitative findings available involving HCPs working with people with intellectual disability and PD diagnoses (Lee & Kiemle, 2015).

The third overarching theme focused on the successful implementation of MDT work which was felt to be vital. This included discussions around reaching good MDT cohesion, sharing specialist knowledge and information, and solving any lack of consensus (e.g., around diagnosis) with open and honest conversations-all of which were seen as powerful enablers of positive working environments and better clinical outcomes. Unlikely to be unique to PD diagnoses, the importance of MDT work in intellectual disability services in general has been highlighted several times (Jones, 2006; Ndoro, 2014). However, most HCPs also felt that they lacked specialist training around PD as well as key members of staff within their MDT (e.g., practitioner psychologists or psychiatrists) who would be qualified to facilitate a PD diagnosis. Again, this finding mirrored previous results involving gualified nurses, who also expressed a desire for more specialist training and education (Lee & Kiemle, 2015).

Some of the limitations affecting MDTs were also seen by HCPs as a reflection of the impact of provision issues and barriers to service access, which shaped the fourth and last theme. These included problems such as interpreting most presentations only through the lens of intellectual disability (diagnostic overshadowing), the consequent friction between services due to intellectual disability diagnoses preventing access to mainstream care, and having to work a highlydemanding and challenging job with low wages and resources leading to issues with staff recruitment and retention. While some of these problems are not new to the field of intellectual disability (e.g., diagnostic overshadowing, low pay; Mason & Scior, 2004; Stevens et al., 2021), many HCPs felt that these challenges particularly impacted them when they worked with people with a personality disorder label-a finding which aligns with previous research highlighting increased demands in terms of knowledge, resilience, and general clinical management (Lee & Kiemle, 2015; Pridding & Procter, 2008). Ultimately, this led most participants to wish they could receive further guidance and supervision in their daily clinical work, especially in the form of professional and emotional support, which are considered vital when working with people with a diagnosis of PD in general (Bland & Rossen, 2005; Moore, 2012) as well as anyone with attachment and/or personality needs (Carr et al., 2016).

#### 4.1 Strengths, limitations, and future directions

The main strength of the present service evaluation resides in the exploration of the subjective views of staff working with people with intellectual disability and a PD diagnosis, which represents a neglected area in the current literature. More specifically, this built on previous evidence showing that qualitative investigations involving HCPs may provide invaluable insight into clinical factors which could go overlooked in quantitative projects or studies focused solely on service users' perspectives (Coates et al., 2021; Zarotti et al., 2019).

However, a number of limitations should also be considered. First, no people with intellectual disability were included in this project. Although our focus was on HCPs and their experiences during clinical work, triangulating this information with the perspectives of service users and potentially their family members would offer further valuable insight and should be considered in future investigations. Secondly, this was an exploratory service evaluation involving HCPs from a specific clinical setting in the United Kingdom, with no attempt to generalise findings, and our findings may not be representative of the experiences of HCPs elsewhere. Therefore, further gualitative studies recruiting more samples representative of a wider range of settings are warranted in this area.

#### CONCLUSIONS AND CLINICAL 5 IMPLICATIONS

Based on the subjective experience of 15 HCPs, four overarching themes were identified as relevant to clinical work with people with both intellectual disability and a diagnosis (or traits) of PD. These included (a) diagnostic issues and the need for person-centred approaches, (b) challenges and adjustments to working with people with combined intellectual disability and PD diagnoses, (c) the importance of MDT training, support, and cohesion, and (d) provision issues and barriers to service access.

The present results show the potential to highlight a number of clinical implications, which may help inform future clinical management and service improvement in similar clinical settings. More specifically, clinicians working with people with both intellectual disability and PD diagnoses or traits may wish to consider the adoption of person-centred and narrative approaches during the assessment process. This would be especially helpful to validate service-users' experiences and provide tailored clinical formulations which account for the high diversity of factors leading to complex presentations and specific clinical challenges such as dependency and risk. Indeed, formulationbased approaches may be seen as playing a pivotal role not only in person-centred care, but also in the understanding of the early trauma and attachment difficulties which often underlie the history of individuals who may attract a PD diagnosis later in life (Carr et al., 2016; Kramer, 2019).

HCPs may also need to be aware of their own assumptions around PD diagnoses (whether positive or negative), the potential for diagnostic overshadowing and inter-service friction, and the

JARID

effect these may all have on clinical decision-making and service access.

Finally, the need for additional MDT training and support, along with clinical supervision and guidance, may be further highlighted when working with people with combined intellectual disability and PD diagnoses, particularly due to increased professional and emotional demands on HCPs.

### ACKNOWLEDGEMENTS

The authors would like to thank the healthcare professionals who participated in the project.

### FUNDING INFORMATION

The authors have no funding sources to report.

### CONFLICT OF INTEREST

The authors declare no conflict of interest.

### DATA AVAILABILITY STATEMENT

Data available on request from the authors.

#### ORCID

Nicolò Zarotti b https://orcid.org/0000-0002-8129-6151
Paul Fisher https://orcid.org/0000-0003-4232-1198

#### REFERENCES

- Alexander, R. T., Chester, V., Gray, N. S., & Snowden, R. J. (2012). Patients with personality disorders and intellectual disability—closer to personality disorders or intellectual disability? A three-way comparison. Journal of Forensic Psychiatry and Psychology, 23(4), 435–451. https://doi. org/10.1080/14789949.2012.694462
- Alexander, R., & Cooray, S. (2003). Diagnosis of personality disorders in learning disability. *British Journal of Psychiatry*, 182(Suppl 44), 28–31. https://doi.org/10.1192/bjp.182.44.s28
- Arthur, A. R. (2003). The emotional lives of people with learning disability. British Journal of Learning Disabilities, 31(1), 25–30. https://doi.org/10. 1046/j.1468-3156.2003.00193.x
- Bland, A. R., & Rossen, E. K. (2005). Clinical supervision of nurses working with patients with borderline personality disorder. *Issues in Mental Health Nursing*, 26(5), 507–517. https://doi.org/10.1080/01612840590931957
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/ 1478088706qp063oa
- Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological (Vol. 2). American Psychological Association. https://doi.org/10.1037/ 13620-000
- Carr, A., Linehan, C., O'Reilly, G., Walsh, P. N., & McEvoy, J. (Eds.). (2016). The handbook of intellectual disability and clinical psychology practice (2nd ed.). Routledge. https://doi.org/10.4324/ 9781315739229
- Coates, E., Zarotti, N., Williams, I., White, S., Halliday, V., Beever, D., Hackney, G., Stavroulakis, T., White, D., Norman, P., & McDermott, C. (2021). Patient, carer and healthcare professional perspectives on increasing calorie intake in amyotrophic lateral sclerosis. *Chronic Illness*, 174239532110690, 174239532110690. https://doi.org/10.1177/ 17423953211069090

- Cooper, S. A., & Van Der Speck, R. (2009). Epidemiology of mental ill health in adults with intellectual disabilities. *Current Opinion in Psychiatry*, 22(5), 431–436. https://doi.org/10.1097/YCO.0b013e32832e2a1e
- Cresswell, J. (2007). Qualitative inquiry and research design: Choosing among five approaches (2nd ed.). Sage.
- Flynn, A., Matthews, H., & Hollins, S. (2002). Validity of the diagnosis of personality disorder in adults with learning disability and severe behavioural problems preliminary study. *British Journal of Psychiatry*, 180, 543–546. https://doi.org/10.1192/bjp.180.6.543
- Harper, D., & Thompson, A. R. (2011). Qualitative research methods in mental health and psychotherapy. In A guide for students and practitioners. Wiley-Blackwell.
- Jones, A. (2006). Multidisciplinary team working: Collaboration and conflict. International Journal of Mental Health Nursing, 15(1), 19–28. https://doi.org/10.1111/j.1447-0349.2006.00400.x
- Kramer, U. (2019). Case formulation for personality disorders. Elsevier. https://doi.org/10.1016/C2016-0-04810-6
- Lee, A., & Kiemle, G. (2015). "It's one of the hardest jobs in the world": The experience and understanding of qualified nurses who work with individuals diagnosed with both learning disability and personality disorder. Journal of Applied Research in Intellectual Disabilities, 28(3), 238–248. https://doi.org/10.1111/jar.12125
- Mason, J., & Scior, K. (2004). "Diagnostic overshadowing" amongst clinicians working with people with intellectual disabilities in the UK. Journal of Applied Research in Intellectual Disabilities, 17(2), 85–90. https:// doi.org/10.1111/j.1360-2322.2004.00184.x
- Milinkovic, M. S., & Tiliopoulos, N. (2020). A systematic review of the clinical utility of the DSM-5 section III alternative model of personality disorder. In Personality disorders: Theory, research, and treatment (Vol. 11, pp. 377–397). Educational Publishing Foundation. https://doi.org/ 10.1037/per0000408
- Moore, E. (2012). Personality disorder: Its impact on staff and the role of supervision. Advances in Psychiatric Treatment, 18(1), 44–55. https:// doi.org/10.1192/apt.bp.107.004754
- Moreland, J., Hendy, S., & Brown, F. (2008). The validity of a personality disorder diagnosis for people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 21(3), 219–226. https://doi.org/10.1111/j.1468-3148.2007.00399.x
- Mulder, R. T. (2021). ICD-11 personality disorders: Utility and implications of the new model. Frontiers in Psychiatry, 12, 10–14. https://doi.org/ 10.3389/fpsyt.2021.655548
- Ndoro, S. (2014). Effective multidisciplinary working: The key to highquality care. British Journal of Nursing, 23(13), 724–727. https://doi. org/10.12968/bjon.2014.23.13.724
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1–13. https://doi.org/10.1177/ 1609406917733847
- Pridding, A., & Procter, N. G. (2008). A systematic review of personality disorder amongst people with intellectual disability with implications for the mental health nurse practitioner. *Journal of Clinical Nursing*, 17(21), 2811–2819. https://doi.org/10.1111/j.1365-2702.2007.02269.x
- Rayner, K., Wood, H., Beail, N., & Nagra, M. K. (2015). Intellectual disability, personality disorder and offending: A systematic review. Advances in Mental Health and Intellectual Disabilities, 9(2), 50–61. https://doi. org/10.1108/AMHID-04-2014-0007
- Sayer, A. (2000). Realism and social science. Routledge.
- Stevens, M., Moriarty, J., Manthorpe, J., Harris, J., Hussein, S., & Cornes, M. (2021). What encourages care workers to continue working in intellectual disability services in England? Interview findings. *Journal of Intellectual Disabilities*, 25(1), 13–30. https://doi.org/10. 1177/1744629519854648
- Torr, J. (2003). Personality disorder in intellectual disability. Current Opinion in Psychiatry, 16(5), 517–521. https://doi.org/10.1097/00001504-200309000-00005

- Webb, Z. (2014). Intellectual disabilities and personality disorder: An integrated approach. Pavilion Publishing and Media https://books.google. co.uk/books?id=lyB9oAEACAAJ
- Zarotti, N., Coates, E., McGeachan, A., Williams, I., Beever, D., Hackney, G., Norman, P., Stavroulakis, T., White, D., White, S., Halliday, V., McDermott, C., HighCALS Study Group, Archer, R., Baird, W., Boddy, M., Bradburn, M., Cade, J., Cooper, C., & Young, T. (2019). Health care professionals' views on psychological factors affecting nutritional behaviour in people with motor neuron disease: A thematic analysis. *British Journal of Health Psychology*, 24(4), 953–969. https://doi.org/10.1111/bjhp.12388

How to cite this article: Zarotti, N., Hudson, C., Human, H.-R., Muratori, G., & Fisher, P. (2022). 'It's working together with what you've got': Healthcare professionals' experiences of working with people with combined intellectual disability and personality disorder diagnoses. *Journal of Applied Research in Intellectual Disabilities*, 35(6), 1317–1326. <u>https://doi.org/10.</u> <u>1111/jar.13020</u>