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Experiences of being diagnosed with an intellectual disability: a mixed methods service evaluation

Authors

Charlotte Grahame[1]
Gregg H. Rawlings[2,3]
Thomas R. Gourley[3]
Nik Vlissides[3]

Affiliations:

[1] Clinical Psychology Unit, University of Sheffield, UK
[2] Psychology Department, Nottingham Trent University, Nottingham, UK
[3] Adult Learning Disability Health Service, South West Yorkshire Partnership NHS Foundation Trust, UK

Corresponding Author:

Dr Gregg H. Rawlings, Psychology Department, Nottingham Trent University, Nottingham, UK, gregg.rawlings@NTU.ac.uk

Co-Author email addresses:

Cgrahame1@sheffield.ac.uk
Thomas.Gourley@swyt.nhs.uk
Nik.Vlissides@swyt.nhs.uk

Orcid ID

G Rawlings - 0000-0003-4962-3551

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Abstract

There is limited research into adults' experiences of being assessed and diagnosed with an intellectual disability (ID). We asked ten individuals referred to an adult learning disability health service for suspected ID, to complete a questionnaire within six months of diagnosis. Questions focused on the pre-, during- and post-assessment. It was common for clients to experience confusion about the diagnosis. The majority found the assessment acceptable, although most still had questions after their diagnosis. Results highlight the need for service flexibility and potential adaptations. Findings contribute to the dearth of evidence, provide directions for service development, and inform person-centred care.

Key words: Learning disability; qualitative; WAIS; neuropsychological testing; diagnostic assessment

Easy to read summary

- We wanted to find out, what it is like to be diagnosed with an intellectual disability.
- We contacted some of our clients, who we had recently diagnosed. We asked them what they thought about the assessment and being diagnosed.
- Some of the things they told us were: They felt anxious before the assessment. They did not really know what an intellectual disability was. They were really happy with clinicians at the service. They preferred to have easy-to-read information about the diagnosis.
- It is important that we listen to people with an intellectual disability so they can tell us what they think about the care they receive and help us do things better in the future.

Introduction

In the United Kingdom there are clear guidelines on how to assess an individual with a suspected intellectual disability (ID) (British Psychological Society, (BPS) 2015). The first stage (1) involves gathering preliminary information such as via a diagnostic interview in which the individual (and usually an informant who knows them well) is asked a series of questions about their history and current functioning, including developmental information; family and living circumstance; past and ongoing difficulties relevant to an ID; health and wellbeing; education; employment and (dis)abilities. If clients are able, they will then (2) undergo an assessment of their intellectual functioning, for example administration of the Wechsler Adult Intelligence Scale- Fourth UK Edition (WAIS-IV; Wechsler, 2008). Alternatively, if clients are unable to complete an assessment even with reasonable adjustments, a best interest decision may be made whereby the diagnosis is based on clinical judgment by a qualified healthcare professional, such as a clinical psychologist. Finally, an (3) assessment of the client's adaptive behaviour is administered which may involve an informant being asked to detail specific skills across a range of domains in relation to the client. After these stages, (4) the outcome of the assessment is shared with the individual and if appropriate, their social support.

The importance of examining clients' experiences of assessment and treatment to help improve the delivery of care has long been recognised. For example, understanding that clients receiving neuropsychological assessments can feel stressed, unnerved, and uncertain about what to expect, can help practitioners to adapt their approach to prevent such difficulties from arising or further support clients once these challenges have been identified (Angélique et al., 2021). There is a plethora of evidence investigating experiences of being assessed and diagnosed with a range of neurological conditions, including autism spectrum conditions (ASC; Jones et al., 2014; Milner et al., 2019), motor neurone disease (Remm, Halcomb & Stephens., 2019) and Parkinson's disease (Schrag et al., 2018). This evidence has helped to demonstrate the potential emotional, social and interpersonal complexities that can be associated with receiving a diagnosis.

In relation to ID, the BPS recognises that giving an individual the diagnosis can have a negative impact on how individuals are perceived and treated by others and themselves. Despite this recognition, there is a surprisingly limited amount of research exploring how adults' experience the process of an ID assessment and subsequent diagnosis. Indeed, research in this area has tended to examine people's account of everyday life with ID, how they view the impact of their diagnosis (Merrells, Buchanan & Waters, 2019; Orr & Goodman, 2010) and experiences of seeking care (McCormick et al., 2020), or they have focused on parental experiences of their child being diagnosed with an ID (Fernández-Alcántara et al., 2017; Rogers, 2007).

We are only aware of two studies examining the person's perspective. Szivos and Griffiths (1990) interviewed five individuals suggesting that the process of coming to terms with the identity of an ID involved six progressive stages including: denial, statement, recognition, exploration, meaning and acceptance. However, this study was conducted over thirty years ago and so may not reflect people's current experiences. For example, since that study there have been advancements in the assessment of an ID, and increased availability of treatments and support for this group of individuals. Furthermore, there is now a greater awareness and sensitivity of the condition within society, such as commonly used terms at that time including "mental retardation" and "mentally handicapped" becoming outdated. More recently, Kenyon, Beail and Jackson (2013) interviewed eight people (seven men and one women) about their diagnosis, three-to-twelve months post-diagnosis. Data were examined using interpretative phenomenological analysis. Participants were also described as going through a process of accepting their disability. This was believed to be a lengthy process, which is important given the average age of their sample was 47 years old and the majority had been diagnosed in childhood. Therefore, their experiences may not be reflective of individuals who have just been diagnosed. Individuals did not identify their disability as global, but rather recognised impairments in particular domains. Participants defined an ID as what they could not do, with no recognition of any positive impact of their disability. The diagnosis itself was described as a difficult experience, but one that symbolised the availability of practical support.

Considering the limited evidence base, we conducted a service evaluation to explore adults' experiences of being assessed for and diagnosed with an ID. Our aims were to examine (1) client's experiences of the assessment and diagnostic process itself (e.g., length of assessment, method of feedback, clinicians' approach as being consistent with clinical guidelines); and (2) clients understanding of an ID. Implications for practice and future research are discussed.

Method

The service

The service is part of an adult learning (intellectual) disability community health service in the North of England serving a population of over 245,000 people. The diagnostic process delivered by the service consists of four stages:

1. A diagnostic interview to assess capacity and obtain consent, diagnostic counselling, collate relevant information for an ID, complete a risk assessment and assess psychological distress and positive wellbeing using the Psychological Therapy Outcome Scale (version II) (Vlissides et al., 2017).

2. If the clinician deems there is sufficient evidence to support the need for a full assessment following the first session, and if the client is able, clients would receive an assessment of their intellectual functioning (IQ), typically using the WAIS-IV (Wechsler, 2008)
3. If appropriate (i.e., based on information gathered from the client's diagnostic interview and if their assessment of cognitive functioning suggests they may have an ID), an assessment of their adaptive behaviour is performed with an informant.
4. Finally, a diagnosis is made based on the evidence collected. This would be given in-person or over the phone depending on the client's preference and explained in a report sent to the client, their general practitioner and referrer.

Stages one to three may be undertaken by a qualified clinical psychologist, or either a trainee clinical psychologist or assistant psychologist under the clinical supervision of a qualified clinical psychologist. Stage four is typically completed by a qualified clinical psychologist.

The current service evaluation was approved by the University of Sheffield and registered and approved by the quality improvement and assurance team within the Trust. As ethical approval was not required, it was not sought.

Clients

Data were collected between January and February 2022 by a second-year trainee clinical psychologist. Clients were eligible to take part if they had been diagnosed with an ID at the service between August 2021 and February 2022. A time limit was set of six months since diagnosis to help reduce memory bias and the heterogeneity of the sample.

Recruitment

The psychology department's database was searched to identify clients who had been referred to the service for an ID assessment and who were given a diagnosis in the appropriate timeframe. The trainee clinical psychologist approached the diagnosing clinician to assess if they thought their client would be eligible to take part in the service evaluation. Please see Figure 1 for reasons why clients may have been judged as not eligible. Clients were then contacted via telephone by the trainee clinical psychologist and invited to take part. All interviews were conducted via telephone. This was a practical decision as it reduced demands on the service - as the trainee did not have to visit the client in the community or book a room - and on the client - as they were not required to come into the service. We are also aware videoconferencing is not appropriate for many of our service users (Rawlings et al., 2021). We have discussed this method of data collection in the limitations. All clients were informed of the study, what their participation would involve, the benefits and risks of taking part, and what to do if they wished to withdraw their data at a later date. All clients verbally provided informed consent to take part and for their information to be used for the purpose of this report which would be shared with others. The trainee clinical psychologist assessed client's capacity to give consent and any problems were raised in clinical supervision. Clients who agreed to take part were asked a series of questions via phone by the trainee clinical psychologist from a mixed-methods questionnaire.

Measure

To develop the mixed-methods questionnaire (see Appendix A), a literature search was first conducted to make sure no existing questionnaire was available or could be adapted.

While none were found, there was research to suggest individuals with ID accessing services valued clear and structured information (Trustman et al., 2022). Consideration was given to the sequencing of questions which addressed the research question. For example, items were ordered in accordance with the diagnostic assessment process. Clear and simple language was used throughout with the use of prompts. The questionnaire was presented at the psychology team meeting for feedback. Finally, the questionnaire was initially piloted on one to two of the clients who had taken part in the study with no further revisions needed.

Data analysis

Rates of recruitment and client's demographics were analysed using descriptive statistics. In accordance with research reporting the findings from a mixed-methods questionnaire that aimed to guide the delivery of care (Rawlings et al., 2021), a mixed-method embedded research design was used. Quantitative data were first analysed with qualitative data being used to help develop, supplement or expand on key themes emerging from the data. Given the modest sample size, particular relevance was given to negative cases (also known as contradictory or deviant cases; Anderson, 2010).

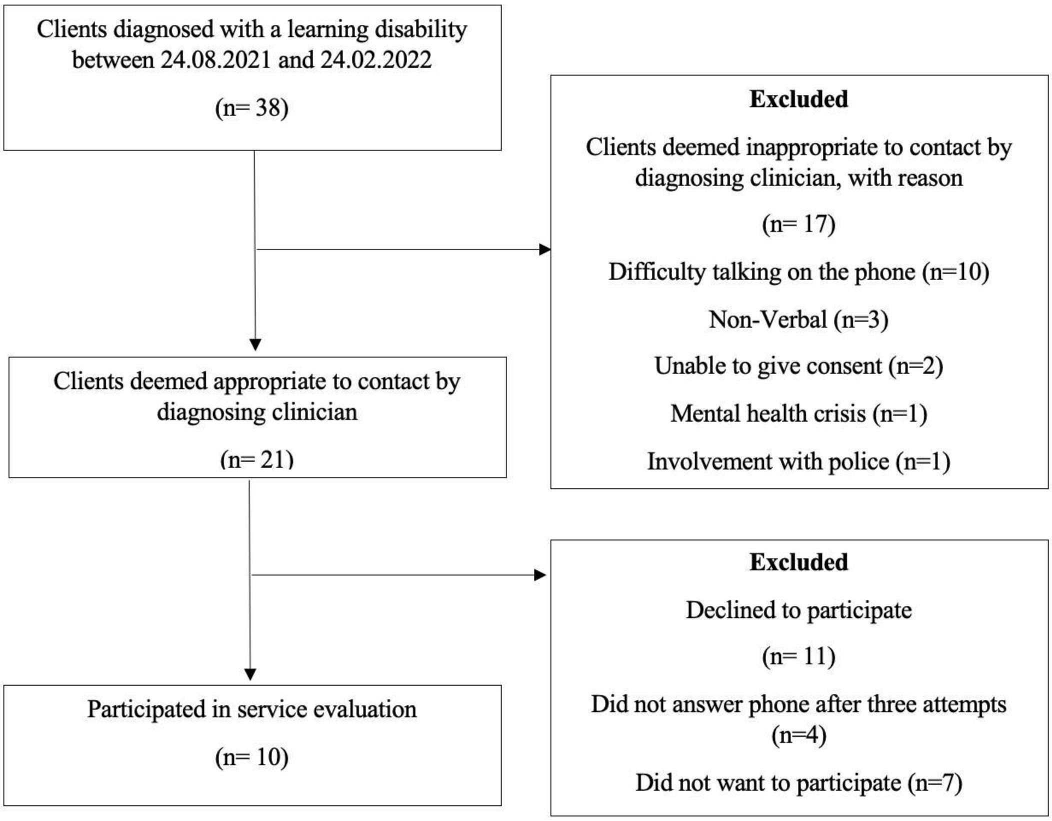
Results

Clients

A total of 38 individuals were diagnosed with an ID by the service within the eligible timeframe. Of whom, 21 were assessed as being appropriate to take part in the evaluation by the diagnosing clinician. From this group, ten participated in the evaluation (see Figure 1).

The mean age of clients included in the analysis was 26.5 years (SD=15.6). Clients had a mean IQ of 58.1 (SD=9.3), putting the majority within the mild ID range. Seven clients identified as female, and 100% were white British (for context, only 7% of the population in the district the service is in are of other ethnicities).

Figure 1 Recruitment rates



Pre-assessment - stage 1

Clients were asked four questions in relation to the pre-assessment stage. Eight clients reported feeling anxious about their appointment. Only four clients knew what an ID was before their appointment, with four also reporting that they had never heard of the term ID before the session. Clients' responses to open-ended questions were consistent with these findings, suggesting it was common for clients to express some confusion about the diagnosis. For example, two clients reported they "*didn't know*" what an ID was, and at least one person struggled to describe an ID - even though this had been explained to them during the diagnostic process. There was a feeling that participants understood what an ID was by relating it to their own personal difficulties; "*you can struggle with things, like I do at school*" and "*I can't read so when someone else can pick something up, I can't".*

Assessment – stage 2 -3

Clients were asked eight questions about stages two to three of the assessment. All clients agreed that the clinician had helped them to feel comfortable in the assessment, and also that they found it helpful to attend the appointment with someone they knew. A consensus was also observed regarding the assessment itself, with nine clients agreeing the questions they were asked were ok and eight agreeing that the session length was appropriate. Overall, nine of the ten clients were satisfied that the clinician had explained who they were and their role; and agreed that the reason for the referral and the assessment was described to them in a way that they understood.

Open-ended questions related to the assessment phase appeared to reflect the challenges that clients experienced during the assessment itself, with evidence supporting this coming from seven of the clients. For example, two individuals spoke about the assessment as "*a bit confusing*" and one felt they "*struggled".* Moreover, clients explained, "*It was difficult, I would not do a lot. I tried. But I was nervous*" and "*It was hard and challenging*".

As discussed, clients valued having a member of their support with them; "*I liked having my dad there*". Reasons for this varied, with clients feeling that their families could understand and support them with their diagnosis and reduce anxieties about the assessment; "*my daughter can support me more*"; "*helped me feel calm*".

Five clients described the clinician as helpful and being "*very kind and clear*". Clients appeared to appreciate the clinician building a rapport with them: "*I liked that he talked to me* *about my likes* [hobbies and interests]. *It was nice*". Three clients expressed that clarity was important for the assessment and clinicians: "*explained everything really really clearly*" and "*I liked that they repeated what they said as I can get confused*". On the other hand, three clients felt aspects of the process could have been improved, for example by "*simplify*[ing] *how you explain the puzzles*". One client also felt the assessment could be further adapted as "*I get confused and it is hard to remember everything. Sometimes things need to be written down in a way I understand*". Of course, this may be challenging given the standardised nature of the assessments used.

Post-assessment – stage 4

Eleven questions were asked about this stage of the assessment and how clients made sense of the diagnosis. Only four clients agreed that they understood what an ID was, with eight individuals feeling that other people knew what an ID was better than them. Therefore, it was not that surprising to find seven clients agreeing that they would have valued speaking to a member of staff about their diagnosis. Indeed, two clients felt that having more contact and support after their diagnosis may have helped them to understand their condition more: "*More contact after diagnosis, I just felt I was left".* Only two people reported that they knew what support was available for people with an ID.

Regarding the final report - a document given to clients which summarises the assessment and diagnosis and offers general recommendations - four clients agreed that someone had read the report to them. Although five agreed that they could understand the report, nine felt that they would have liked an easy-read document about ID.

Client's preferred method of contact to be informed of their diagnosis was mixed, with eight clients being happy to be contacted to be told of their diagnosis, five agreeing they would have been happy to receive the diagnosis in person (with the other five disagreeing), six being happy to receive the diagnosis over the phone, and nine disagreeing that they would have wanted to receive their diagnosis in a letter.

When examining client's responses to the open questions, for some there was a sense of relief at receiving the diagnosis. It was felt that this validated their awareness of feeling different when they had compared themselves to others, as one client described; "*I knew I was different*". The diagnosis could provide an understanding of why they felt the way they did, with one person explaining, "*It is nice to finally know what it is*". Another client reported that, "*I felt glad that I had been diagnosed, it has been tossed aside for years but I'm different and that has always been clear for me*". One client expressed frustration that they did not receive their diagnosis earlier, "*I am pleased that I was diagnosed, I thought it should have been done when I was little* [younger]".

Two clients felt a sense of indifference toward their diagnosis expressing that it was *"alright*" or "*ok*". For another client however, there was a feeling they were still processing what a diagnosis meant for them, "*I don't know, I feel embarrassed I think*".

Discussion

This evaluation aimed to explore adults' experiences of the process of diagnostic assessment of an ID, and their understanding of the condition. There is limited evidence in this area, with previous research either being conducted over 30 years ago or recruiting a heterogeneous sample, which while identified important findings, may not reflect individuals accessing services for a suspected ID. In the current article, results have been separated into the clinical stages of a diagnosis; however, we recognise not all clients will feel this order of events reflect their lived accounts.

Overall, there were high levels of satisfaction observed in terms of the clinician's approach to the assessment. All or most clients agreed that they had been supported to feel comfortable; the clinician had introduced themselves, reason for referral and stages of assessment were explained; and the length of the assessment and questions they were asked were appropriate. Indeed, these aspects of care have been reported by clients elsewhere as being important for their experience of services (Crane et al., 2016). This suggests that both the structure of the existing pathway, and the way clinicians deliver it, are acceptable. This acceptability could account for why the majority of clients did not report anxiety during the assessment, but did report feeling anxious ahead of it. That said, it would be an inference to suggest this is because anxiety was not present or had been reduced by clinicians' manner.

It is somewhat worrying that over half of the clients interviewed did not know what an ID was before or even after their assessment. Indeed, the individual referring the client should have gained informed consent from the client to make the referral and clinicians will have discussed the condition with the client. This finding may not necessarily be due to oversights by referrer or clinicians, however. It may be explained by other reasons, including the client struggling to explain the diagnosis to another person or the client forgetting the information.

When it came to receiving their diagnosis, client's experiences were varied. Most clients agreed that they wanted clinicians to contact them and for the diagnosis to be delivered by conversation. This is consistent with our current approach; however, the preferred method of contact varied between in-person and over-the-phone. The findings demonstrate the importance of flexibility from clinicians, and of clients being involved in deciding how their diagnosis will be delivered early on in their journey. As extrapolated from clients' descriptions here, the aim of this should be for the information to be discussed in a format that they could understand.

Consistent with the literature, clients were found to personalise their diagnosis (Kenyon et al., Jackson, 2013), for example defining it by specific difficulties they experienced. Therefore, it is worth considering whether individuals struggled to understand more global definitions of ID because they did not correspond with their own experience. Nearly all clients reported wanting information in a format they could understand, with some reporting either not having read or understood the report. This may also suggest why clients struggled to define an ID. This highlights a need for feedback sessions to be adapted to include easy read reports which focus on specific strengths and weaknesses the client has, so they can relate their diagnosis personally, rather than globally; in addition to the technical reports produced for services. By offering a tailored report, and promoting a strengths-orientate approach to care, the process offers the potential to contribute positively to client's post-diagnosis.

Results show that clients experienced varying emotions regarding their diagnosis. For some, acceptance was clear, and they were left with a sense of relief as their diagnosis provided them with answers. However, others were still processing what the diagnosis meant for them or were unsure how to feel about it, whilst some described a sense of post-diagnosis abandonment. These findings suggest that some clients could benefit from a follow-up stage, to offer post-diagnosis counselling, support and/or guidance based on the client's needs, such as access to financial, social and psychological support. This again highlights the need for clinicians to be flexible in their delivery of care.

It is important to recognise that out of the 38 clients who had been assessed in the six months prior to this service evaluation, only 21 (55%) were evaluated to be eligible to take part – with ten participating. Consequently, these findings reflect one quarter of clients referred to a health service for suspected ID. Greater efforts are needed to capture their experiences of the process, in particular those from non-White backgrounds and/or with more severe forms of ID who may struggle to engage in self-report research. Furthermore, collecting data over the phone, excluded a large proportion of clients with communication difficulties. Approaches may include greater adaptations such as using images to help explain questions and asking individuals who attended with clients, based on observable behaviour, how they think the client was treated.

In summary, while evidence has helped to glean insight into people's experience of living with an ID, the current study has shed light on accounts of the diagnostic process itself and how individuals process being given the diagnosis. We know that people with an ID can experience challenges in everyday life associated with ID, however client's accounts here have helped to focus on the difficulties they experience with the diagnosis. In turn, these experiences have highlighted a number of adaptations to improve clients' diagnostic experience and better support the understanding of their diagnosis.

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Appendix A

Questionnaire

During the diagnostic assessment	**1**	**2**	**3**	**4**
	Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
Before my first appointment, I had heard of the term learning disability				
Before my appointment, I knew what a learning disability was				
Before my appointment, I knew some people with a learning disability				
I was anxious about my first appointment				
The member of staff explained who they were and their role				
The reason I was referred was explained to me in a way that I understood				
The assessment was explained to me in a way that I understood				
The member of staff answered any questions I had (may be NA)				
The member of staff helped me to feel comfortable about the assessment				
I found it helpful attending the appointment with someone who knew me (may be NA)				
The length of the sessions was ok				
The questions I was asked were ok				
I was happy someone contacted me to tell me I had a diagnosis - rather than reading it in a letter				
I would have been happy to receive my diagnosis in person				
I would have been happy to receive my diagnosis over the phone				

I would have been happy to receive my diagnosis in a letter				
Someone read the report of my assessment to me				
I could understand the report I received of my assessment				
I would have liked easy-to-read information on learning disability after my diagnosis				
After my diagnosis, I understood what a learning disability means				
After my diagnosis, my family and friends understand better what a learning disability is				
I know what support is available for people with a learning disability				
I would have liked to speak to a staff member about my diagnosis after my assessment				
I would recommend the service to a friend				

Open ended question

How would you describe to somebody else, what a learning disability is?

How did you feel being diagnosed with a learning disability (has it changed the way you think or feel about yourself)?

What did you think of the assessment for a learning disability? (*how was the assessment, the session, how did you find the personal protective equipment?)*

What was most helpful during your assessment and why?

How would you improve the service your received?

Is there anything else you would like to say?

Thank you for your time