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Waiting for psychological therapy during the COVID-19 pandemic: Experiences of adults with an intellectual disability

Abstract

Purpose: Measures introduced to mitigate the spread of Coronavirus-19 (COVID-19) may have contributed to an increase in waiting times for face-to-face psychological treatments. As adults with intellectual disabilities (ID) are more likely to encounter barriers when accessing remote therapies, it is important they receive appropriate support while waiting. To understand what care is needed, this service evaluation explored the experiences of service users with ID who have waited for treatment during the pandemic.

Methods: Seven individuals who had been waiting for psychological therapy during the COVID-19 pandemic, which included those waiting longer than the NHS target of 18 weeks, were interviewed. Data were analysed using framework analysis.

Findings: Four key themes were identified: (1) *Waiting has been "painful",* related to how service users continued to experience difficulties whilst they waited; (2) *Tolerating the wait,* highlighted that individuals understood the reasons for waiting; (3) *Use of coping strategies* where service users identified both internal and external strategies they had used to cope; and (4) *Support and contact from the Learning Disability team*, related to how individuals experienced the support they received from the service.

Originality: This service evaluation is the first to explore the experiences of service users with ID waiting for psychological therapy during the Covid-19 pandemic. Results guide suggestions on improving support whilst they are waiting to help prevent further decline.

Keywords: Psychological therapy, Intellectual Disability, Waiting lists, COVID-19, Service evaluation, Mental health

Introduction

Since March 2020, varying restrictions have been in place in the United Kingdom (UK) – and around the world - to help manage the spread of coronavirus disease (COVID-19) (UK Health Security Agency, 2020; UK Health Security Agency, 2021). Such measures have led to mental health services modifying how treatments are delivered, such as reducing capacity to deliver face-to-face psychological therapies (NHS England and NHS Improvement, 2020). Indeed, remote delivery of interventions have been promoted, which have allowed treatments to continue to be delivered to some degree (British Psychological Society, 2021). However, it has been recognised that engaging in remote therapies may be more challenging for those with intellectual disabilities (ID) (Rawlings et al., 2020). This has unfortunately and inadvertently resulted in reduced access to support (The Scottish Commission for People with Learning Disabilities, 2020; Lunsky et al. 2022) and lengthier waiting times for treatment in ID services (Purrington & Beail, 2021).

Research in the general adult population indicates that COVID-19 and the associated restrictions have posed numerous challenges for those with mental health difficulties, including a loss of support and increased isolation (Alzueta et al., 2020; Salari et al., 2020). These challenges are likely to be particularly pertinent for those with an ID, given that stressful life events and lack of social support are linked to an increase in the likelihood of a mental health diagnosis and behavioural difficulties (Scott & Havercamp, 2014). Indeed, studies exploring the experience of those with ID and mental health difficulties during the pandemic, have highlighted reports of a disruption to daily life, difficulties in accessing services, less connectedness and confusion regarding COVID-19 restrictions (Embregts et al., 2020; Lake et al., 2021).

Despite national restrictions being linked to reduced numbers of referrals for mental health support (Purrington & Beail 2021; Larrson et al. 2022), there is a general pattern of longer waiting times for psychological therapy, as well as treatment in general (Cooke et al. 2022; Purrington & Beail 2021; Griffin, 2020). Long waits have been shown to negatively impact patient outcomes

(Reichert & Jacobs, 2018), typically leading to an increase in missed initial appointments (Carter et al., 2012; Claus & Kindleberger, 2002; Mitchell & Selmes, 2007) – although not always (see Yates, Brittleton & Beail, 2022) - and act as a barrier to seeking support (Adams & Young, 2021; Anderson et al., 2017). Moreover, studies investigating the use of waitlist control groups have also indicated that being on a waitlist can be inferior to receiving no treatment at all. It is hypothesised that this may be due to individuals on waiting lists being less likely to seek out alternative sources of support, due to the expectation that if they continue to experience difficulties, they will receive their originally desired therapy (Furukawa et al., 2014). This highlights that long waiting times may be detrimental to those experiencing psychological distress.

Although there is a paucity of research regarding the impact of waiting for psychological therapy on individuals with ID, there are findings to suggest it negatively impacts wellbeing (Burke, 2014), and has increased psychological distress within the context of the COVID-19 pandemic (Purrington & Beail, 2021). In fact, long waiting times may be particularly challenging for those with ID, who find stressful situations more difficult to manage due to their perception that they are less able to cope (Janssen et al., 2002). The pandemic and associated restrictions have meant that individuals with ID waiting for therapy have already had to tolerate a large degree of uncertainty (Courtenay & Perera, 2020). They may have also found it difficult to make use of existing coping strategies whilst waiting, due to overwhelming amounts of information they have had to process, reduced social contact and increased amounts of time spent in the home away from activities and distractions (Courtenay & Perera, 2020; Embregts et al., 2020). This means that long waiting times in the context of the pandemic may have been particularly problematic for those with ID.

It is also important to recognise that uncertainty regarding the pandemic has continued into 2022 following the emergence of the new variants, continued high levels of COVID-19 across the globe and the newly identified condition, long COVID (post COVID-19 syndrome) (World Health Organisation, 2022; Rawlings & Beail, 2022). At the time of writing, many restrictions remain within NHS services for people with learning disabilities that may continue to impact the length of time that service users wait for therapy. Research exploring the experience of waiting for psychological therapy for those with ID is lacking. It may benefit services to understand this experience, especially as waiting lists continue to be disrupted and in the event of lengthy waiting lists in the future.

We conducted a service evaluation with the aim of investigating the experiences of individuals with ID who have waited for psychological therapy in the context of a global pandemic (between March 2020 – March 2022). Qualitative approaches have been recognised as a valuable tool in research for people with ID, particularly when exploring service user experiences (Beail & Williams, 2014). This evaluation therefore adopted a qualitative approach to derive themes from service user experiences of waiting for psychological therapy. Implications for future research and practice within our service are discussed.

Methods

The service

The service evaluation was conducted in an NHS community adult Learning Disability (LD) health service in the North of England. It serves a population of 244,600. The psychology team within the service provides psychological therapy (including psychodynamic psychotherapy, cognitive behavioural informed therapy and third wave therapies); diagnostic assessments for ID, ASD and cognitive decline; behavioural support; and consultation to the wider multi-disciplinary team, carers and third sector services.

Following the initial lockdown in March 2020, the service significantly reduced face-to-face appointments in response to the COVID-19 pandemic, which was in line with local and national guidance. Service users were offered virtual appointments via telephone or video call where appropriate (see Rawlings et al., 2021); however, for some, treatments and diagnostic assessments were postponed until a more suitable time. Introduction of infection prevention and control strategies allowed for a gradual increase in face-to-face appointments from June 2020. Despite this, some restrictions were in place at the time of writing. These restrictions ensure that social distancing can be maintained in clinic rooms and waiting areas, sanitisation and air ventilation can occur between sessions and that foot flow through the clinic is reduced.

Service users

Service users on the waiting list who met inclusion criteria were first identified. To be eligible for inclusion in the current service evaluation, individuals must have had a diagnosis of ID, (which was confirmed at the point of referral to the service by consulting the local learning disability register). Clients will have been assessed for an ID by an appropriate healthcare professional (i.e., Clinical Psychologist) and based on the presence of lower intellectual ability (such as an IQ of less than 70), significant social or adaptive functioning impairment, and difficulties observed in childhood. Clients must have had the ability to provide informed consent to take part in the evaluation, communicate via telephone and have been on the waiting list for psychological therapy during the COVID-19 pandemic, which included those waiting for longer than the NHS target of 18 weeks (NHS, 2019). Service users who did not meet this criteria (i.e., people who could not provide consent due difficulties associated with the severity of their ID or unable to communicate via phone) were not eligible to take part – we have discussed this in the limitations.

Data Collection

The lead author attempted to contact everyone on the waiting list who met the inclusion criteria. Service users were contacted between February- March 2022 via telephone on a maximum of two occasions. Telephone interviews were chosen over face-to-face interviews to reduce the burden on service users; for example, clients did not have to travel to the service or navigate remote technologies, which we know can be challenging for the majority of our client group (Rawlings et al., 2020). An information sheet and a consent form were read out to each service user. All service users included in the service evaluation provided informed consent to take part, and for their data to be used for the purpose of this report. Service users who consented undertook a semi-structured interview. Capacity to consent was assessed by the lead author; for example, all clients were evaluated as being able to understand and retain the information provided, weigh up their decision to take part and communicate their response.

Consultation with the service's Psychology team was sought to ensure the interview schedule addressed topics that would be helpful for the service. The interview schedule consisted of three sections: the impact of waiting for psychological therapy, coping with difficulties whilst waiting for psychological therapy, and support from the Learning Disability team during their wait. Feedback on the experience of being interviewed was also sought from participants at the end of the interview by the interviewer (lead author), which included an open-ended question asking clients whether they wished to discuss anything else in relation to the evaluations aim. Interviews were audio recorded and subsequently transcribed. Interviews ranged from 5 to 15 minutes in length.

Data analysis

Framework analysis was used to analyse the data (Ritchie & Spencer, 1994). This method of analysis was selected due to its epistemological flexibility, which allows pre-determined areas to be explored in line with what is important to the service and relevant in the literature, whilst also allowing for data driven themes to be identified (Parkinson et al., 2016; Ritchie & Spencer, 1994). This method also allowed the contextual and evaluative nature of the service evaluation question to be explored (Ritchie & Spencer, 1994).

The five analytical stages of 'Framework' were followed: familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation (Ritchie and Spencer, 1994). The framework was initially based on a priori information to include themes, such as the impact of COVID-19 on waiting and the use of coping strategies. This was then applied to the interview transcripts, adapted, and refined to allow for cohesion with emerging issues from the data, such as having no one to talk to during the wait and limitations to coping strategies.

The project was commissioned by the service lead and approved and registered with the Trust's Quality Improvement and Assurance Team. As the service evaluation was complete as part of the lead author's training in clinical psychology, the protocol underwent an internal review at the Clinical Psychology Unit, University of Sheffield. As it was a service evaluation, ethical consent was not required and therefore not sought.

Results

Service user sample

Overall, 17 service users were eligible to participate of whom, seven consented to taking part (four women, three men: age range 23-63). Reasons for referral for psychological treatment included, depression (*n* = 4), anxiety (*n* = 1), voice hearing (*n* = 1) and trauma (*n* = 1). There were several reasons why service users did not take part including, they did not answer the phone (*n* = 5), their carer answered and felt the service user would be unable to participate (*n* = 4), or client's answered but it was an unsuitable time and could not re-arrange (*n* = 1).

Findings from framework analysis

Table 1 presents the themes and subthemes identified from the analysis.

Table 1 Themes and sub-themes

Themes	Sub-themes
1. Waiting has been ‘painful’	1.1 Difficulties remained 1.2 Negative impact of COVID-19 1.3 No one to talk to about difficulties 1.4 Additional stressors whilst waiting
2. Tolerating the wait	2.1 ‘I understand why I’m waiting’ 2.2 No concerns about psychological therapy
3. Use of coping strategies	3.1 Internal coping strategies 3.2 External coping strategies 3.3 Limitations to coping strategies
4. Support and contact from the learning disability team	4.1 Received no support 4.2 Received helpful support 4.3 Desire for additional support and contact 4.4 Awareness of how to contact the team

Theme One: Waiting has been “painful”

All services users expressed that waiting for psychological therapy had been difficult in some way. Four subthemes were identified:

Theme 1.1: Difficulties remained

All service users who were interviewed reported that they continued to experience the same difficulties for which they were initially referred for psychological therapy, with some feeling that their difficulties had worsened whilst waiting. However, at least one service user noted that despite their difficulties remaining, they had somewhat "*settled down*".

> *"I just want someone to stop me from hearing the voices, it's doing my head in." [SU 4]*

> "*Sometimes it's worse and some days it isn't." [SU5]*

> *"It's made them* [symptoms] *worse, yeah" [SU1]*

Theme 1.2: Negative impact of COVID-19

Six service users felt that COVID-19 and the associated restrictions negatively impacted them whilst they were waiting for psychological therapy. Service users reported how COVID-19 meant that they were unable to engage in their usual activities, access services or see family and friends:

> "*It* [COVID-19 restrictions] *has, because I've been feeling low. I couldn't engage with my sports or go anywhere or do nothing." [SU1]*

> *"Obviously, I couldn't speak to my doctor during the crisis* [COVID-19 pandemic] *because they couldn't see anyone* [reduced face to face appointments at GP surgery]*" [SU6]*

> *"It's been bad…really bad. There's been no one to talk to or anything" [SU1]*

> *"I'm not used to stopping in the house that long… I've been… it's just been terrible, it's been upsetting, it's stressful"* [SU3]

Theme 1.3: No one to talk to about my difficulties

The lack of support in terms of not having somebody to talk to about their difficulties was a common subtheme. This was something service users felt made the wait for psychological therapy more difficult:

> *"It's been painful because I haven't been talking to anybody." [SU3].*
>
> *"Been hard* [waiting for therapy]... *Not talking to anybody. Isolating myself from people. Not having nobody there to support me." [SU7]*
>
> *"It's made them worse, yeah...Having no one to talk to and that." [SU1]*

Theme 1.4: Additional stressors whilst waiting

The impact of other stressors, beyond the difficulties for which service users were initially referred for, were also commonly described during interviews. Such stressful circumstances appeared to arise throughout their wait for psychological therapy and made life more difficult. These included stressors, such as housing and social care issues, physical health or other medical conditions, and pregnancy.

> *"I've got an injury on my knee. I've got to start going on a diet now because they've told me if I start eating all the fatty stuff, I could get diabetes." [SU3]*
>
> "[Asking how have things been] *I really want to move. There's a place... would be a lot better for me." [SU5]*
>
> *"I had an accident three weeks ago... and I broke my arm.... I've been having bad headaches and my vision keeps going and I keep thinking 'oh what if it's this, what if it's that?' but that's the health anxiety." [SU 6]*

Theme Two: Tolerating the wait

Despite the challenges associated with waiting for psychological therapy, there was a general theme of being able to tolerate the wait. Within this, two subthemes were identified:

Theme 2.1:: "I understand why I'm waiting"

Service users were understanding of the need to wait for psychological therapy and being aware of the impact of COVID-19 on their waiting time and service provision:

> *"You can only do what you can do. I'm not bothered as long as someone can sort it out for me." [SU4].*
>
> *"With the pandemic, obviously, it can't be helped, it's affected a lot of people, not just myself and stuff so I understand why I'm wating for it." [SU6]*
>
> *"It's affected me in so many different ways but obviously you can't help COVID and that." [SU7]*

Theme 2.2: No concerns about psychological therapy

Service users did not identify any concerns about attending psychological therapy. Waiting did not appear to create anxiety about psychological therapy and service users continued to express a wish to attend:

"*I've been through it all before* [psychological therapy]*, so I know what to expect and what not to expect type thing." [SU7]*

> *"I don't mind it* [starting psychological therapy]*, I don't mind it at all" [SU3]*
>
> *"I'm excited to get back to it again. If that's what you mean?" [SU6]*

Theme Three: Use of coping strategies

Service users were able to identify various coping strategies they had used throughout their wait that seemed to help improve their waiting experience. They also showed awareness of the problems associated with some of these coping strategies. Three subthemes were identified:

Theme 3.1: Internal coping strategies

All service users who took part in the evaluation identified some internal coping strategies that they have used whilst waiting for psychological therapy, which have helped them to manage their difficulties. These strategies included watching television as a distraction, breathing exercises, making to do lists, and engaging in activities that made them feel they had a purpose:

> "*I volunteer in a charity shop. If I hadn't got that I would've gone mad by now." [SU5]*

> *"Sometimes being on my own lets me get my thoughts together and actually having a plan in my head of what's going to happen in the morning. Or I do a list and basically drag me* [my] *self out of bed and do it." [SU7]*

> *"I watch the telly, I like my music as well. And going for walks now and again when it's not that cold" [SU3]*

> *"I just turn the TV up louder to get the voices out of my head"* [SU4]

Theme 3.2: External coping strategies

This subtheme concerned the importance of other people in helping service users to manage their difficulties. Service users identified support workers, family, friends, and pets as sources of support. It appeared that service users benefited from practical and emotional support from those around them. Two service users had noticed that medication had also helped them:

“*Loads of support* [from support worker]. *They* [support worker] *take me all over. If I want to go out, I go out.” [SU2]*

“*My helper* [support worker] *when she's here, the voices calm down, I don't hear as much.” [SU4]*

“[Coping with the wait for therapy] *I've just really been getting on with it and obviously my medication* [has helped*]. I see* [psychiatrist] *every three months and I see* [nurse] *every week so it tides me over.” [SU7]*

“I've been out with support workers now and then. Been able to go out more than that” [SU1]

Theme 3.3: Limitations to coping strategies

Despite all service users identifying some helpful coping strategies, some noticed limitations to their coping skills. For example, during times where they were unable to use them and when they resorted to unhelpful strategies, such as searching symptoms on the internet which increased their anxiety.

“I'd just look up [symptoms] *on internet which is a bad way to go about it… because obviously for me it was my health anxiety … if you search your symptoms Google's going to throw something at you what's not true” [SU6].*

“It [beathing exercises and meditation] *does help sometimes but if I'm too far on, if you know what I mean, it doesn't work.” [SU6]*

“*It distracts me but then I go downhill.” [SU1]*

Theme four: Support and contact from the learning disability team

This theme discussed service users' experience of receiving support from the learning disability team whilst waiting. Four subthemes were identified:

Theme 4.1: Received no support

Five service users could not recall receiving any support from the learning disability team throughout their wait for psychological therapy. In one case, this was due to a family member acting as main point of contact, therefore the service user stated that they were unsure. There was a general sense that this made service users feel forgotten about:

> *"I've only got* [support worker's name]. *[...] Not since this call today. I haven't heard nowt* [nothing]. *" [SU3]*
>
> *"Other than the support worker and that, it's* [support from the learning disability service] *not been good" [SU1].*

Theme 4.2: Received helpful support

Two service users however identified support they had received from the learning disability team during their wait, which they felt had been helpful. These included members of the psychological team who they had spoken to on the phone, during their initial assessment (triage) with a qualified Clinical Psychologist or having input from the other professionals such as nursing:

"The doctor I went to see about it, he was helpful. Very helpful. He were [was] *good. You all have been, the lot of you. [...] when I sat down and talked to him, he took all the pressure off me." [SU4]*

"[Nurse] *helps me through meetings or if I need to let something out I can talk to her."[SU7]*

Theme 4.3: Desire for additional support

Five service users felt that they would benefit from additional support from the learning disability team whilst they wait. Most people expressed a desire to have a regular check-in call and update from the team regarding their place on the waiting list. One person felt that worksheets and resources sent out in the post during the wait would be beneficial:

"*Come and see me and explain what's going on* [with waiting for therapy], *give me an update." [SU1]*

"If they [the learning disability service] *contacted me like every now and then to see how I'm getting on and maybe like, send some sheets out maybe what you can learn at home."* [SU6]

Theme 4.4: Awareness of how to contact the team

All but one service user was aware they could contact the learning disability team and had been given the service's phone number. Being aware of the contact details for the service helped service users seek support when they needed, usually, but not always, resulting in a beneficial effect on their wellbeing:

"I have rung them [learning disability service] *up before a few times and there's been someone… If I speak to someone it helps sometimes. But sometimes it doesn't." [SU6]*

"*I've got the phone number somewhere but I may have lost it so you may need to send it out to me so that if I need owt [anything], I can phone them and talk to somebody there" [SU3]*

Discussion

This service evaluation aimed to explore the experiences of adults with ID who had been waiting for psychological therapy during the COVID-19 pandemic. Service users identified that waiting was difficult, and their symptoms had remained throughout their wait. The uncertainty of the wait did not seem to exacerbate difficulties or increase anxiety around attending appointments for psychological therapy in the future. Most felt that the absence of someone to talk to about their difficulties made the wait more challenging. Contrary to our initial thoughts based on previous research (e.g., Janssen et al 2002), most service users did not notice a deterioration in their mental health and were understanding of the reasons for waiting. Future investigations are required to quantitively examine the association between waiting for psychological therapy and mental wellbeing. More specifically, research designs should be used that allow for the identification of factors that influence this relationship, which could then be used to inform practice. For example, service users here expressed a desire for their wait to be acknowledged and for them to have regular contact with the service. This is in line with research with service user groups in other settings, that suggest people value their feelings about waiting for support being validated (Gagliardi et al., 2021).

Clinical implications

There are several measures that could be taken to reduce the burden of waiting. Services could aim to identify those waiting longer than a set period and contact them when the target is breached. A conversation about their wait may validate any difficult feelings and help reassure those concerned about the length of their wait. This could also be an opportunity to remind the service user of their pre-existing coping strategies or support from services in the community. Service users on the waiting list who have previously received therapeutic input could be identified and resources from their previous therapeutic episode could be shared. This may be particularly important for those who are not in receipt of support from other teams within the service. Although there are limited self-help material available for people with ID, resources which have been created show promising results in helping service users manage their mental wellbeing (Maguire et al. 2022; Jahoda et al. 2017). As services users in the current sample desired additional support, such resources could be disseminated more often to increase their use of internal coping strategies while enduring the wait for face-to-face input. Of course, such strategies need to be piloted first before being adapted in routine practice. In addition to assessing service user satisfaction, exploring whether this approach impacts attendance, engagement and outcome of therapy would also be helpful.

A service strategy for greater input while waiting for therapy is desirable considering that a lack of social support has been linked to an increase in the prevalence of mental health difficulties in those with ID (Scott & Havercamp, 2014). Indeed, although a range of internal coping strategies were identified and employed by service users, they could not always be accessed due to restrictions, and sometimes became challenging to use when distress levels were higher. As found by Courtney and Perera, (2020) and Embregts (2020) the restrictions associated with the pandemic will have meant that service users had less social contact, reduced access to their internal coping strategies, and an inability to rely on others when their internal coping strategies were ineffective. Therefore, strategies to help services users waiting for therapy should include a mixture of self-help material, regular communication with the service and methods to increase contact with the community.

The evaluation highlighted the value of practical support from others, such as help paying bills and accessing the community. Outside of the pandemic and associated restrictions, this level of support may have been more readily available to service users waiting for psychological therapy, however, since the pandemic, restrictions and pressures on services have meant that this level of input has not been possible for many (Embregts et al., 2020; Lake et al., 2021). The pandemic has therefore likely made the wait for therapeutic input more challenging by impacting service users' ability to access practical support. Professionals working with individuals with ID who have been waiting for psychological therapy, should be mindful that they will have had fewer options for support for example due to restrictions – this is patricianly salient due to the current economic climate associated with the rising cost of living. They may have also experienced additional stressors during their wait. This could mean their circumstances have changed and social determinants of mental health and wellbeing have been affected (Lake et al., 2020). This may impact the focus or suitability of therapeutic input and require a more systemic approach to psychological support, and increased communication with third sector services. Moreover, service users may value being re-assessed before starting psychological work to explore any changes in desired goals of therapy, clinical need and risk.

Better methods of managing waiting lists could also be implemented. Limited session models and adhering to the stepped approaches to care could be considered to increase the speed at which service users complete treatment, freeing up clinician time to offer therapy to those on the waiting list. This has been effective in some services at reducing wait times whilst maintaining positive outcomes (Thomas et al., 2021). For example, in the service being evaluated, service users would sometimes attend initial sessions no longer requiring therapeutic input. These service users could be removed from the waiting list and clinician time could be freed up by setting up review calls with clients prior to initial sessions to understand whether therapeutic input is still indicated. It is important to note however, that there is a paucity of research empirically testing these methods in populations with ID. Indeed, services should be cautious of using approaches that may inadvertently contribute to the difficulties that this clinical group already encounter when accessing services.

It is positive to note that service users reported no increased anxiety about coming to psychological therapy due to the increased wait. Therefore, unlike other services (Livianos-Aldana et al., 1999; Gallucci et al., 2005; Mitchell & Selmes, 2007), an increase in waiting time may not lead to an increase in non-attended appointments in the learning disability service. This is supported by empirical data from the same service demonstrating that the onset of COVID-19 and increased waiting times for an appointment did not influence attendance rates for initial psychology appointments (Yates et al., 2022).

Limitations

Although this evaluation highlighted important themes in the experiences of people with ID waiting for therapy, the transferability of these themes to other sub-groups is limited by the modest sample size of seven people from the same geographical area. Moreover, all participants were interviewed over the phone which meant that individuals with more severe communication difficulties were unable to take part. Indeed, the option of face-to-face interviews using communication aids could help recruit service users with a moderate or severe ID, making the results more relevant to the wider population with ID. Additionally, we could have collected richer data, for instance, examining non-verbal communication. Furthermore, we could have sought the support of caregivers of service users to help them to engage in the evaluation. That being said, the fact carers were unaware of service user's responses, may have allowed them to be more open and honest; for example, not being concerned about how their carers would feel about their difficulties. One area for future research is to explore experiences of non-professional caregivers of adults with ID waiting for therapy during the pandemic. Indeed, the current evaluation highlights that external social support was important to a service user's wellbeing while waiting for professional care. Carers are often the ones who provide this support and the need for it may have been even greater during the pandemic, which may have presented unique challenges – especially at a time when their own resources of coping were limited.

Finally, service users (or caregivers) were not consulted regarding the topic guide – nor were the findings shared, for example for member checking to confirm we captured client's descriptions correctly. Similarly, the interview schedule was not piloted first on a small number of individuals. Failing to utilise service user and public involvement to guide what questions to explore in the interview may have resulted in key themes being missed in the interview procedure. However, service users were given opportunity to add anything that had not previously been mentioned and were encouraged to speak freely throughout the interviews.

Conclusions

This study is the first to qualitatively investigate services users' experiences of waiting for psychological therapy in an ID service during the COVID-19 pandemic. As such, findings provide a starting point for further exploration of these themes using a larger heterogeneous sample. It was revealed that service users found the wait challenging for various reasons and that they had a desire for additional support or contact during their wait. However, participants were able to use coping strategies and support from others, which made the wait more tolerable. It is hoped that these experiences will help learning disability services to understand the impact waiting for therapy has on service users and consider ways to reduce the burden of waiting, both in the current circumstances and in the event of lengthy waiting lists in the future. Research to empirically test the effectiveness of waitlist management strategies in populations with ID would be beneficial in supporting these service users in the future. This stage is required before strategies are implemented in routine practice.

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