Developing digital approaches for adolescents and young adults with autism and learning disabilities: Tools to facilitate access and shared decision-making

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Aims: *Digital living is now an integral part of many children and young people's (CYP) everyday experience. Practitioners who work with them are increasingly focused on effectively deploying technology to help those with social, emotional and mental health (SEMH) needs. Throughout all aspects and phases of work, practitioners must adhere to legal and professional best practice standards in involving service users, person-centred working and in enhancing accessibility for all.*

Methods: *Measures introduced to reduce the spread of Covid-19 triggered significant service delivery change in a specialist multi-disciplinary child and adolescent mental health service (CAMHS) team. The majority of assessment and intervention work moved to an online audio and web conferencing platform. A shared decision-making approach was developed to support service user understanding of online appointments and to giving informed consent, in line with the i-THRIVE Framework for system change (Wolpert et al., 2019). Three Guides were developed and distributed ahead of online appointments: written, easy-read and video.*

Findings: *Data collected within a Quality Improvement (QI) framework indicated that the Guides supported practitioners to prepare service users, as well as themselves, for digital working. The Guides supported service access, collaborative decision-making and increased CYP autonomy. Their introduction also led to conversations about equity and cultural responsiveness, as well as serving as a model for the development of aids to support shared decision-making for autism diagnostic assessments.*

Limitations: *This paper outlines the first phase of the QI project with a small participant sample and requires further engagement with service users to review the use of Guides and shared decision-making decision aids.*

Conclusions: *Digital approaches present new possibilities and are rapidly changing service delivery across CAMHS. The importance of involving service users in shared decision-making when developing digital practices must be held in mind as part of this change process.*

Keywords: *Digital approaches; shared decision-making with adolescents; social, emotional and mental health needs; autism; i-THRIVE.*

ADOLESCENCE is a time of profound personal growth and development (Blakemore, 2018; Waddell, 2018). Expectations of young people also change, with diverse views on how and when they can make more independent

decisions about their lives. Given that this is 'a critical period during which [young people] establish health-promoting behaviours that will contribute to their present and future well-being' (World Health Organization (WHO), 2020, p.1), understanding this decision-making in its community and cultural context is essential. Much psychological work in this developmental phase takes place in a wider milieu of digital living, given that adolescents have been 'early and enthusiastic adopters of digital technologies' (Odgers & Jensen, 2020, p.336). Texting and using smart phone applications (apps) are everyday modalities to engage with and be engaged by friends, peers and others. YouTube is a popular video sharing platform and online synchronous platforms such as Zoom and MS Teams facilitate face-to-face interaction for multiple purposes. Digital approaches are distinctive in terms of (i) speed of access, (ii) breadth of new ideas available, (iii) capacity for personalisation, and (iv) the ways in which they permit not only passive asynchronous content consumption but also real-time interaction with content (and indeed, the creation of one's own content) (Chassiakos et al., 2016). It is of paramount importance to consider the intersection of digital approaches to psychological assessment and intervention with professional and ethical standards as regards service user involvement and person-centred ways of working.

In March 2020, CAMHS provision changed almost overnight in response to the Covid-19 pandemic. Physical distancing measures impelled the introduction of online audio and web conferencing platforms. This paper outlines the first phases of a Quality Improvement (QI) project focused on shared decision-making, initiated prior to the pandemic and then developed in response to the changing profile of service user and provider need during this time. The literature on the use of digital approaches with CYP with additional needs is reviewed, situated in wider professional and ethical systems of person-centred ways of

working. QI as a methodology is summarised and decision aids developed to assist access to digital psychological services described. Practitioner views on the use of these tools are explored thematically, and connections made to the literature. Finally, strengths and limitations are examined, and possible future directions explored.

Literature overview
Children and young people's mental health in the digital age
Technological gains have transformed the ways in which many CYP experience and make sense of the social, educational and, where applicable, therapeutic world around them (Hollis et al., 2020). There is a diversity of viewpoints in the literature on whether this transformation is a positive or negative one. Some have argued that digital living adversely impacts physical health and increases feelings of loneliness, social isolation and low mood (Perret et al., 2020; Piteo & Ward, 2020; Stiglic & Viner, 2019; Twenge et al., 2018). For others, digital approaches offer new opportunities for CYP to access mental health services, enhance help-seeking behaviours and effectively address some common mental health difficulties (Cliffe et al., 2020; Hollis et al., 2017; Merry et al., 2020; O'Dea et al., 2020; Spence et al., 2020). Nevertheless, questions about the effect sizes, methodological quality and generalisability of many studies in this area remain (Kardefelt-Winther et al., 2020; Piteo & Ward, 2020; Odgers & Jensen, 2020). Hollis and colleagues used the evocative image of a triple-edged sword to convey the complexity of research and practice in this area, noticing that digital 'immediacy, portability, intimacy, unconstrained reach and lack of supervision and regulation of content' (2020, p. 837) influence young people's mental health in multi-directional ways.

Service user involvement: International and national contexts
Digital technology developments have occurred alongside long-standing interna-

tional and national calls for young people, including those with mental health needs and disabilities, to be included in decisions that affect them (Aston & Lambert 2010; Bjønness et al., 2020; Hughes et al., 2018; Pearl, 2013; Smilie & Newton, 2020; UNICEF, 1989; WHO, 2012). The Revised Special Educational Needs and Disabilities (SEND) Code of Practice highlighted key principles relevant to service user involvement, including person-centred working generally and supporting CYP and parents/carers to participate in decisions about their support specifically (DfE, 2015). Codes of ethics centre acting in the best interests of service users and emphasise personal responsibility for promoting and protecting these interests (Health & Care Professions Council, 2016). Making service user involvement a reality, however, is complex. Barriers include potential risks to the CYP's emotional welfare, assumptions about capacity, time available, the consequences of sharing (e.g. where the CYP view is critical of parts of the system) and so on (Boland et al., 2019; Harding & Atkinson, 2009; Kennedy, 2015; Warshak, 2004). Understanding the possibilities and pitfalls of digital approaches in the context of service user involvement is overdue.

Shared decision-making (SDM)

SDM refers to a relational, interactive and collaborative decision-making process between CYP, their families and the practitioners working with them (Adams & Levy, 2017; Boland et al., 2017; Légaré et al., 2011). It is a cornerstone of service user involvement, and indeed has been positioned as a fundamental goal of the health service overall (The King's Fund, 2011). Evidence indicates SDM positively impacts on a person's own understanding of their needs, their self-confidence and self-esteem, satisfaction with care and responsiveness to intervention (Abrines-Jaume et al., 2016; The Health Foundation, 2012; Langer & Jenson-Doss, 2018). Especially noteworthy are meta-analyses that demonstrate SDM reduces inequalities and promotes the inclu-

sion and empowerment of traditionally excluded groups (Durand et al., 2014). It is unsurprising, therefore, that SDM is one of the key principles of the child and adolescent mental health i-THRIVE Framework for systems change (Wolpert et al., 2019). The framework provides a set of principles for communities of mental health and wellbeing support, emphasising a common language understood by all and where 'mental health needs are defined by children, young people and families alongside professionals through shared decision making' (Wolpert et al., 2019, p.3).

Implementing SDM in practice with CYP and people with disabilities is not without its challenges. Where there is interest in doing so, more attention has been paid to parent/carer involvement than to disabled children and young people themselves (Adams & Levy, 2017). In the autism literature, decision-making has been associated with increased rates of anxiety and exhaustion, leading to problems making decisions and a tendency to avoid it (Luke et al., 2012; Zellner et al., 2016). Of particular relevance to the present study is a systematic review on the barriers and facilitators to SDM carried out in 2019. These included (i) the quality of information available to inform SDM and the degree to which this was tailored to any given situation, (ii) the tools and resources provided to support SDM, and (iii) the quality of relationship between CYP, their families and the practitioners working with them (Boland et al., 2019). The potential or otherwise of technology in personalising and improving SDM, including scope for the development of SDM tools, warrants further attention.

Boland and colleagues' review (2019) emphasised providing quality information tailored to developmental and literacy levels in SDM; presenting options for next steps with associated risks and benefits. Environmental facilitators of SDM highlighted included access to training, resources (e.g. decision coaches) and decision aids. The International Patient Decision Aid Standards Collaboration define decision aids as tools

to provide information on the care options available and to help people communicate their own values and preferences. An aid does not provide advice on choosing one approach over another; and nor does it replace dialogue between service user and practitioner. There have been multiple research studies on the use of decision aids. A recent Cochrane review stated that 'when people use decision aids, they improve their knowledge of the options and feel better informed and more clear about what matters most to them… and probably participate more in decision-making… people and their clinicians were more likely to talk about the decision when using a decision aid' (Stacey et al., 2017, p.3). The ways in which digital technologies could be harnessed in decision aids to provide information tailored to need, to facilitate space for discussion and to enhance value-informed dialogues about options appears less well attended to.

Digital approaches and autism

Text-to-speech software, robotics, artificial intelligence, social communication apps, smartphones, tablets, interactive whiteboards and online digital environments generally are approaches familiar to many autistic people and those who work with them (Zervogianni et al., 2020). Reasons given for this proliferation include the degree to which technology can (i) support engaging and sustaining the interests of people who may often be oriented towards visual stimuli and who may show a preference for logic, predictability and structure, and (ii) make communication more straight-forward and less demanding in terms of reducing the cognitive load of interpreting nuances in tone, idiom, facial expression and gesture (Goldsmith & LeBlanc, 2004; Grandin, 2006; Wojciechowski & Al-Musawi, 2017). Indeed, Reicher (2020) reported that during the pandemic, autistic learners in her clinical practice preferred online learning to the extent they resisted the return to in-person education. However, digital approaches in the context of mental health care for autistic CYP are not without

their limitations. The evidence base for many of the digital supports used by and for autistic people is variable (Zervogianni et al., 2020). In terms of using synchronous real-time platforms, establishing rapport and trust can be more challenging, confidentiality is not always easy to maintain and their use may impact on the identification of and effective work with more subtle autism presentations (Solomon & Soares, 2020).

Digital approaches in mental health during the pandemic

Responses to the pandemic changed the quantity and quality of digital working, although robust studies of what changed and its impact are, understandably, yet to come (Kaess et al., 2020). Bekes and colleagues (2020) investigated practitioner experiences of therapy provision during the first lockdown and found the majority felt confident and competent delivering therapy online. McBeath and colleagues (2020) surveyed psychotherapists working online at this time (N=335) and more than half reported that such work had been effective. They also reported advantages such as increased client access to mental health support, increased client choice of provider and reductions in travel and time costs. However, thematic analysis also highlighted disadvantages: connectivity and time lags impacting in engagement, the difficulties of creating confidential spaces and maintaining boundaries at home and the impact of time spent onscreen providing therapy. What appears absent from survey responses was the 'other pandemic' running rife: racism (Farquharson & Thornton, 2020; Godlee, 2020). No reference to the trauma, including intergenerational trauma, caused by racism on the mental health and well-being of people of African, African-Caribbean and Asian heritages was reported. This is striking, given arguments made that racial discrimination should be treated as the public health issue of our time: 'racism kills people… it is the underlying driver that puts people from ethnic minority groups at the centre of the Covid-19 pandemic… we cannot tackle

Covid-19 unless we tackle racism' (Godlee, 2020, m2303).

As a service, we provide (i) diagnostic assessment for adolescents and young adults with complex mental health needs and social communication differences, and (ii) psychological therapies for children, young people and adults with diagnoses of either learning disability and/or autism and their families. Interventions include family work, psychodynamic psychotherapy, trauma-focused work, systems work, risk support, consultation to the network and so on. The team takes referrals from a number of London boroughs and surrounding areas, resulting in a diverse service user profile in terms of race, culture, faith, sex, gender, socio-economic status and so on. The team has for some time offered a placement opportunity for trainee educational psychologists (TEPs), and is currently managed by an educational psychologist. TEPs may be offered supervisory experiences by clinicians from different professional backgrounds, as well as opportunities to shadow and/or work alongside trainees from different disciplines. They participate fully in the work of the team at individual-in-context (e.g. individual assessment and intervention), group (e.g. designing, delivering and evaluating groups for parents/carers) and service development levels (e.g. quality improvement activity).

Prior to the pandemic, the team had limited previous experience of digital working. A range of factors had contributed to this, many of which have also been identified in the literature, and included:

• the digital divide between groups of service users, reflecting wider socio-economic disparities (including sufficiency of enabled devices, availability of a confidential space in poor/overcrowded accommodation, associated financial costs, etc.)

• assumptions made about engagement, take-up and effectiveness of digital approaches (Hollis et al., 2017; Fleming et al., 2019)

• attitudes and training in using digital approaches (Sanderson et al., 2020; Stoll et al., 2020), as well as in the availability of suitable, secure platforms for service provision.

Given the infection control measures necessary to protect physical health, however, the Trust introduced the platform Zoom for the provision of routine care. For our service users, in-person appointments remained available for risk support and for those whose care would be compromised or could not be provided digitally. An emerging Quality Improvement project on SDM for service users aged 16 and older referred for assessment was adapted to reflect this change. Guides were created to support young people's understanding of Zoom appointments, intended to support giving informed consent to working online and to enhance more independent access to services.

Method
Quality Improvement (QI)
The present study was conducted as a QI project in a specialist mental health trust. QI refers to the systematic use of methods and tools to continuously improve the quality of care and outcomes for service users (Alderwick et al., 2017). While originally applied in industrial and organisational settings, QI began to be utilised in health care in the 1990s (Powell et al., 2009) and improving health care quality is now a key policy priority in the UK National Health Service (e.g. NHS England, 2020). There is a range of QI methodologies and the current QI project was based on the Institute for Healthcare Improvement's Model for Improvement. It is a widely used approach in QI that asks three key questions: *What are we trying to accomplish? How will we know that a change is an improvement?* and *What changes can we make that will result in improvement?* (Langley et al., 2009). Changes are then tested in small iterative cycles, commonly known as Plan, Do, Study, Act [PDSA] cycles (The Health Foundation, 2013) (see Figure 1). As this was a QI initiative, it was registered with the trust's Clinical Governance and Audit Department (Ref. ID 20310).

Figure 1: Model for improvement Plan, Do, Study, Act cycle
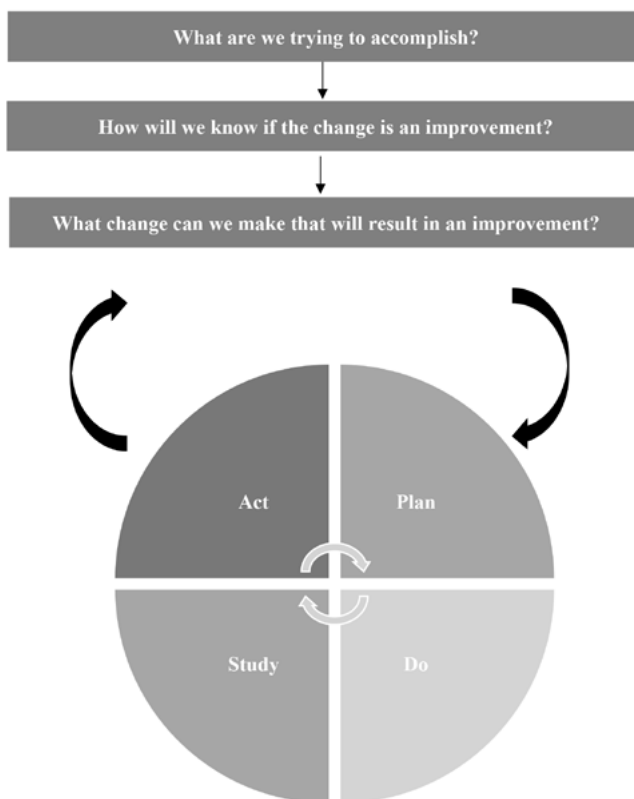
Methods

As part of the *Do* stage of a PDSA cycle, a set of tools were produced and provided to all practitioners. Relevant i-THRIVE principles were used to inform design (e.g. *Common Language, Shared-Decision-Making, Outcome-Informed, Accessibility*) e.g. as an important aspect of Outcome-Informed is ensuring the risks and limitations of service provision are acknowledged at the outset, this was incorporated into Guides and aids.

Zoom Guides

Three Zoom Guides were produced. The first was a written Guide to help service users make a decision about using Zoom and included the following sections: *What does a Zoom appointment involve? How will this help me feel better? Are there any down-sides to this type of help? How long will this be for? Who can I ask for help?* and *What will I need?* (see Figure 2 for an example section of the Guide). The second was a modified easy-read Zoom Guide that used more visuals and included information about setting up and testing the system, as well as strategies for creating a suitable space at home (see Figure 3 for an example section of the Guide). The third was a video Guide, which included team members demonstrating how to prepare for Zoom sessions by modelling finding a confidential space, logging in and selecting preferences (e.g. camera on or off), etc. Team members were sent all three versions of the Guides and asked to share them with service users ahead of appointments and to use the Guides to inform subsequent discussions about options for service provision.

Figure 2: Written Zoom guide example section

~~sides to this type of~~ help?	• Some appointments will need you to find a private space in your home to take place • You might miss being in the room together with your practitioner
How long will this be for?	• At the moment we cannot say how long we will be offering video appointments instead of face-to-face appointments • Our service will follow Public Health guidelines and communicate to you about any changes as soon as we can • You can think about how this uncertainty feels together with a practitioner
Who can I ask for help?	• If you need any help with deciding whether to attend a video appointment you can email ____ or call ____ • If you need any help with accessing a video appointment from your device you can email ____ or call ____
What will I need?	• You will need to have access to a device with a camera • You will need to share a contact number for your parent/carer with your practitioner • Check that Zoom works on your device by clicking on this link: https://zoom.us/test • You will need to find a private space where you feel able to talk • Speak to the other people in your home and make sure they know not to interrupt you • Find somewhere to sit and make yourself comfortable before the appointment

Figure 3: Easy read Zoom guide example section

Video Appointment Guide

You can still talk to a practitioner from our team while you need to stay at home.

The practitioner will send you an email with a link and you can talk to them via video.

At the time of your appointment, click on the link sent in the email to connect to Zoom.

If you'd like to test your browser before your session, you can click on this link https://zoom.us/test to check your equipment and settings.

Figure 4: Assessment decision aid easy read example section

Assessment SDM Aids

Two decision-making aids (the second an easy read version of the first, see Figure 4 for an example section) were created to support decision-making about assessment. The aids adapted the Guide structure to focus on the assessment process and included the following sections: *What does this assessment involve? How will this help me feel better? Are there risks or side-effects to this type of help? Will I see the same person for the duration of this assessment?* and *Will I be given support at the end of this assessment?*

Potential advantages and disadvantages of receiving a diagnosis were then outlined in grid form, based on previous and current service user perspectives expressed following a diagnostic assessment and on the literature (e.g. Attwood et al., 2014). These included: personal (e.g. *It may provide explanations for unanswered questions that you have had about yourself for a long time*), family and home (e.g. *Some family members might not accept the diagnosis*), social and relationships (e.g. *You can choose who you tell*), education and training (e.g. *Special adjustments and accommodations can be made for you to support you in achieving your best*) and employment (e.g. *It might be difficult to decide whether to tell your employer about your diagnosis*). Decision-making aids were stored so that they could be used flexibly by all team members (e.g. via the screen sharing option in Zoom). These aids were piloted with service users (especially those aged 16–25) and parents/carers of all ages to check for clarity and ease of use. Minor alterations to format and wording were made following the pilot phase.

Feedback process

During the *Study* stage of a PDSA cycle, practitioner feedback on the usefulness of the aids was sought. Three practitioners (one clinical psychologist, one TEP and one psychological therapist) provided written feedback via email. Three practitioners (one educational psychologist and two TEPs) participated in an online focus group, facilitated by a TEP

involved in the design of the Guides and aids. Two broad questions informed the discussion: (1) *What are your experiences using the Zoom Guides and/or decision-making aids so far?* and (2) *Are there any ways that you think the Guides and their use can be improved?* The focus group lasted 45 minutes, was audio recorded and transcribed verbatim by the facilitator. An inductive thematic analysis was undertaken on the data gathered through the focus group and email correspondence. This was broadly informed by the six-stage approach to thematic analysis suggested by Braun and Clarke (2006, 2013). The analysis was carried out by the first author and discussed with the other authors. Informed consent was obtained from all participants prior to data collection, including consent to use anonymised participant quotations for publication purposes.

Findings

Three broad themes emerged and are reported on below: (a) containing the transition to online working, (b) promoting access and equity, and (c) empowerment and decision-making. Quotes are used to illustrate themes, chosen on the basis of their ability to reveal something interesting and distinct about a theme, as well as their potential contribution relative to the literature (Watts, 2014).

Containing experiences during times of uncertainty and organisational change

Participants frequently referred to the guides providing a sense of containment. Two of the main sources of practitioner anxiety were the demands posed by new digital practices and concerns around its impact on the service user:practitioner relationship. The guides helped practitioner build their own competence in navigating and explaining online appointments e.g.

> *It was a real shock to the system, and paralysing for a lot of people […] people were like 'how will I manage?' …the guides and the video gave people structure to hang onto […]*

little steps to say 'ok, I can do this bit, I can make this bit happen', and what it did was to create a boundary and a structure which I think … provided some form of containment for the staff (Participant 1)

Participants reported that the assessment SDM aids provided structure for raising sensitive and complex topics while working remotely e.g.

> *I used the assessment guides with the young person mainly around decision-making […] I think that communication with them was a little difficult given the context, so using the assessment guides via this platform was really helpful, and giving them something to go away with and discuss as a family especially when thinking about the informed consent of the 16 year old* (Participant 2)

Access and equity

Assisting access and engagement, especially for service users with English as an Additional Language (EAL) and literacy difficulties, was discussed e.g.

> *I used them on Monday with a family from Turkish-Kurdish background, and I think in terms of EAL it was phenomenally helpful… It's quite abstract language when you're talking in terms of the pros and cons of diagnosis so having the visuals [in the easy read version] made a big difference…[and] the video, it's entirely not dependent on being able to read and write in English or any other language, [it] models and demonstrates* (Participant 1)

Practitioners noted that the Zoom Guides helped service users to prepare for appointments in their own homes, including helping them to move psychologically into a therapeutic space. This was discussed in the focus group as an implicit feature of accessibility, especially for service users that struggle with change e.g.

> *It does really make you think about what we have been expecting young people to be able to*

manage, this dual idea that psychologically we are in a separate space but you are in your own bedroom in your own house... maybe using the guides starts to convey and make some sense of... what we are doing (Participant 1)

Emailing the Zoom Guides to the young person directly rather than to the parent... and that simple thing of it arriving to them, allowing them to test it out, almost testing out moving into that new psychological space where they will see somebody before the actual appointment (Participant 3)

Practitioners considered the benefits of digital approaches, especially for service users with social communication and SEMH needs, linked to the functions that allowed for the camera to be turned off and also text communication e.g.

I wonder if this different way of communicating with service users might be an addition rather than a replacement? Offering a wider range of options may increase accessibility to the [team] (Participant 4)

I have found that with the cameras off especially for those that had real difficulty with their self-esteem... and if you think about the amount of young people that come into the room with their heads down, and kind of using their hair to cover their face, so it kind of broke that down and allowed them to feel comfortable. I think I got more communication from them through this platform (Participant 2)

Issues with supporting and engaging service users without access to technology were also raised. Assumptions that all service users had the necessary financial resources to access Zoom were challenged. In addition, cultural factors also needed to be accounted for e.g.

One of [practitioner's name] families doesn't have the internet or a computer, I think for a religious reason (Participant 1)

Empowerment and decision-making

Participants shared experiences of the Guides facilitating greater engagement with and promoting young people's independence, especially in collaborative decision-making and providing informed consent. Emailing the guides directly to the young person provided more ownership e.g.

They were saying that it felt quite empowering to them and they also said that it reaffirmed the reasons why they were interested in coming to the clinic [...] It seems like the tools help to position them as people who we really really need to get consent from, and we need to make sure that they do understand the process and what they are agreeing to and what the outcome might be (Participant 3)

I was hoping to continue sessions with a young person when we went into lockdown but mum felt that the sessions couldn't be transferred to online, however when I sent an overview letter with the Zoom Guides to the young person, they were able to make that decision for themselves and decided to start online (Participant 2)

Participants reported that the Guides prompted conversations about independence and autonomy e.g.

It kind of came up through looking at the Guides, especially the point about finding a confidential space... he [the parent] was basically thinking that he would be attending the session with his son and I said, 'Your son is 17 and if he was happy to, I think that he is able to attend on his own.' So, it kind of led to some conversations (Participant 3)

Use of the SDM aids in practice also identified concerns and prompted further critical reflection on whether the information included was as effective as it could be in aiding decision-making. For example, when discussing 'pros and cons' of assessment, one participant felt that it presented service users with too binary a view (i.e. that an assessment was either all good with only beneficial

outcomes or all bad with only detrimental outcomes). Whether the language used in the aids was clear enough was also raised, for example, speaking with service users about the difference between an assessment and a diagnosis e.g.

> *It might not be as definitive as yes and no… there will be outcomes, and do outcomes then map onto pros and cons of diagnosis? Outcomes will be different for every individual* (Participant 2)

> *When I was using them the other day… I recognised… that [we] were all getting confused, because there are pros and cons to having the assessment, but also pros and cons to receiving a diagnosis* (Participant 1)

Not all DSM-V criteria are met in every case and a service user may have an assessment but not receive an autism diagnosis. Finally, whether the aids were culturally responsive enough was raised (e.g. whether they adequately addressed the issue of possible stigma and discrimination that could come from receiving a diagnosis).

Discussion
Findings are discussed by theme linked to the literature. Strengths and limitations of the study are then outlined and suggestions for future directions made.

Findings in the context of the literature
Containment during uncertainty and change
The development of the Guides and SDM aids came at a time of adaptation to unprecedented uncertainty. Care must be taken not to pathologise responses; what we know about the impact of Covid-19 and associated infection control measures on CYP's mental health is still emerging and is mixed. However, increased levels of distress and anxiety for many have been reported, with disproportionate impacts on families of key-workers, families already vulnerable prior to the pandemic (e.g. those affected by domestic abuse) and families of African, African-Caribbean and Asian heritages

(Millar et al., 2020; Pearcey et al., 2020; Pereda & Diaz-Faes, 2020; Townsend, 2020). Frontline health workers have also reported symptoms of anxiety, post-traumatic stress, depression and insomnia (Chakraborty, 2020). Some have argued that society at large propelled itself into a disturbed state 'when the 'brick mother' that is appealed to in the phrase 'our NHS' – an institution that can provide safety, care and a containment capable of holding us together when we are at our most vulnerable – is itself perceived to be under immediate existential threat' (Baraitser & Salisbury, 2020, p.6).

It is in this context that the Guides and aids were developed and used. Whilst they were not developed with the explicit intention of supporting practitioners, an unexpected consequence was that they appeared to provide a sense of containment for staff and trainees (Bion, 1959). They gave a way of communicating to both service users and one another what was changing and how, and strategies to be able positively cope with such changes. They also helped convey the sense that work would continue, albeit in adapted form, and that a space for thinking together would remain. Practically, the guides helped practitioners with limited prior experience of digital approaches to develop their technical competence. They also supported navigating sensitive and complex conversations with service users and their families about the transition to online service delivery.

Accessibility and equity
Findings tentatively indicate that exploiting technology in service delivery may promote equality of opportunity and enhance access for some groups of service users; and without comprising ethical and good practice principles around consent and person-centred working. The Guides highlighted to service users and practitioners the crucial importance of moving from the physical space of one's own home to a psychological 'therapeutic space' for appointments, a factor of significance in providing effective digital mental health services (Anthony & Nagel, 2010; Simpson et al., 2020; Solomon &

Soares, 2020). The Guides and aids enabled service users with SEND to access and engage with the service, especially the easy read and video versions. Practitioners who used the Zoom Guides reported that they helped draw explicit attention to key issues such as disabled young people's right to confidentiality and to the need for appropriate levels of independence and autonomy in the context of family interdependence. Using the Guides also facilitated thinking about the novel therapeutic opportunities afforded by functions such as screen sharing, turning the camera on and off and using text communication alongside video, which may have had particular implications for a client group who find social interaction more complex. In one case example, the assessment aids supported SDM with a family for whom English was an additional language, helping the practitioner attend to the intersection of inequalities that may lead to over and under diagnosis of autism in minoritised groups (e.g. Durkin et al., 2017; Henderson & Majors, 2020).

Empowerment of young people

The QI project enhanced existing practitioner discussions about the imperative for shared decision-making tailored to need. The tools, their use and related team dialogues contributed to a further shift in how young people were positioned in their specific community and cultural context. For example, emailing the tools directly to young people may have offered a therapeutic gain by repositioning them as active participants in their own care. Parents/carers of older young people and young adults with SEMH and autism are understandably likely to have had long-standing experiences of making decisions on behalf of their child and of directly interfacing with service providers. Our findings suggest that like many parents/carers, the parents/carers of disabled adolescents and young adults benefit from space to think about their child's right to privacy and their progress towards more independent decision-making, situated in their own unique family and cultural system (Austin et

al., 2012; David, 2018; Tharinger et al., 2013). This is just as relevant with digital intervention, where 'meaningful engagement requires an inclusive and mutually respectful partnership between young people and adults in which power is shared, respective contributions are valued and acknowledged, and young people's ideas, perspectives, skills and strengths are integrated into the design and delivery' (WHO, 2020, p.11).

Strengths and limitations

This study illuminates one aspect of digital approaches to working with adolescents and young adults with complex needs, and the need to preserve and embed principles of person-centred working even at times of great distress, uncertainty and change. There are few studies of shared decision-making in EP practice and this paper perhaps highlights its potential more widely. The study may also demonstrate the possible value of QI approaches for psychology services in that on-going iterative cycles of change – even quite small changes – can be tracked, monitored and measured. As an example, the current service QI work specifically addresses the gaps identified during the PDSA cycle reported here (i.e. increased service user involvement, modifications to language to increase clarity and breadth of perspectives and enhanced cultural responsivity).

There are a number of limitations. QI is not the same as empirical research study and as Helps argued there are essential differences between investigating 'practice solely for the sake of improving this practice and conducting research where the aim is both to improve practice and also to disseminate the findings more widely' (2017, p.352).

Our participant sample, by the very nature of the work, was small, self-selecting and not representative. There was no respondent validation or cross-checks on data coding as would be expected within a research inquiry frame. Moreover, half of the participants provided written feedback via email, which may well have impacted on the richness of the data generated. Our QI

project focus was not on the effectiveness of digital approaches generally but on the Guides and aids alone, and further investigation of the losses and gains of digital working is essential. The *Study* phase of the PDSA cycle took place as the first lockdown response to the pandemic was easing, and where insufficient time had passed to have a more representative and balanced perspective on their use. Most importantly, only the views of practitioners are included here and data on service user views not reported.

Future directions
Implications for our own work include addressing the gaps through further PDSA cycles as identified above. It will be essential to seek further service user views on the utility of the Guides and aids, as well as to continue to add to them. Ensuring as many perspectives as possible are included is crucial, reflecting the diversity of views on autism and diagnosis (Gaffney, 2020; Mogensen & Mason, 2015). In terms of future directions more generally, the wider benefits and challenges of digital approaches to mental health care, especially for disabled young people and/or those SEMH needs, requires further investigation. This will require a recognition of what is potentially gained, such as removing barriers to seeking treatment (Kaess et al., 2020) balanced with potential losses – there is little point in seeking treatment that lacks efficacy in real-world contexts, that does not satisfactorily sustain the therapeutic connection or that does not sufficiently address risk in more vulnerable populations (e.g. Grist et al., 2018).

It is a complicated context within which to move forward: our own experience would suggest that at least some service users express strong preferences for digital working, even when it may ostensibly appear to inhibit their preferred futures (e.g. those for whom leaving their home was a therapeutic goal prior to the pandemic). At the same time, it has been suggested that it this kind of profile, that is, those with 'interpersonal avoidance who may find in-person sessions overwhelming' (Simpson et al., 2020, p.3),

who actually benefit from digitally-accessed therapies. It may be that future work in this area will need to simultaneously address the complexities of multiple interacting factors, such as modality, practitioner training and attitudes towards digital delivery, service user need and preference and so on. Given that even in the literature attending to co-design with CYP in digital health interventions, disabled young people remain under-represented, further research in this area using emancipatory designs may offer new insights and understandings (Hodson et al., 2019; Jones et al., 2020; Thabrew et al., 2018).

Conclusion
At the time of writing, reports of vaccine distribution and a 'return to normal' abound. How and in what ways the pandemic affected the mental health and wellbeing of service users and practitioners in the long term, and whether the use of digital approaches will continue to evolve, remains to be seen. It seems unlikely that we will return to what we did before March 2020, not least because of the economic efficiencies and increased access to services associated with digital approaches. Perhaps blended methods that both make use of suitable technology and preserve 'the essential human connection' will become more familiar (Sanderson et al., 2020). Regardless of what approach is taken, this human connection needs to be just that – a connection between humans, where the essential humanity of the service user is recognised and respected. No decision about me without me has been a rallying cry for at least a decade: it is essential that it is heard in both digital and in-person contexts, and that it is heard when it is made by autistic and learning disabled young people.

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