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Digitally enabled, self-referral as an effective approach for young autistic people to access support: pilot study

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Abstract

Background Limited resources in health and social care and long waiting lists for autism assessment are resulting in high numbers of autistic people not being adequately supported. We sought to explore the feasibility and effectiveness of meeting this support need through an end-to-end digital self-referral and digital mental health service.

Methods Together with health and social care teams and young autistic people we developed a self-referral pathway that allowed young autistic people (aged 16–25) to access the digital self-management support system, Brain in Hand (BiH), without the need for diagnosis or referral by an external agency. Participants were reached using digital media channels which linked to a BiH landing page. Reach, progress and engagement through the pathway was monitored and participants were surveyed on their eligibility and suitability for BiH.

Results A total of 243 BiH licences were issued within 9 weeks of the start of the digital media campaign which reached nearly half a million people with close to 20,000 clicking through to the BiH landing page. Most of the young people being issued with the digital support tool demonstrated high levels of need, 69% experienced clinically significant depression, 83% anxiety, 99% moderate or high executive function challenges, and 60% lacked current support.

Conclusions This pilot demonstrates that young people understand their needs and directing them to a support service through a digital media campaign presents an efficient and effective approach to reaching young autistic people in need. This suggests that digital media channels and self-referral could offer a practical solution to broaden access to a range of digital mental health platforms without placing additional resource burden on health and social care teams.

Keywords Anxiety, Autistic, Depression, Digital, Mental Health, Neurodiversity

Background

Health and social care services are under the dual pressure of high levels of vacancies and staff sickness [7] and increased demand for support [28], especially in the area of mental health. This is particularly pertinent for autistic people, where there are long waiting lists for diagnostic assessment, and no guarantee of obtaining appropriate support for those who do obtain a diagnosis [5]. In practice, support is often restricted to those with very severe

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needs, despite evidence that autistic people experience anxiety and are at high risk of self-harm [3, 17]). Given that early intervention among autistic adolescents can build resilience and help prevent mental health difficulties [31], opportunities are being missed to support people effectively, and early enough. Innovation is needed in service access and service delivery to meet the demand and to improve prevention efforts.

Delivery of support services most frequently involves an initial referral by a professional, followed by an assessment, before any decision is made about whether support can be provided. This approach introduces barriers to receiving appropriate support [13] and is not effective at engaging vulnerable populations. Self-referral, where an individual decides themselves that they need support, can mitigate many of these barriers and is commonly used by charities and in the private sector. Self-referral, for example, is a key aspect of the Improving Access to Psychological Therapies (IAPT) programme within NHS England [6], more recently renamed NHS Talking Therapies. As of 2020, there were over 200 IAPT services across England [34] which have significantly increased access to psychological therapies.

Given the high numbers of autistic people, 1.8% of young people [27], and suggestions that as many as 72% of autistic people in England are undiagnosed [22], any service providing support for those self-referring needs to be scalable. High levels of smartphone ownership and the increasing role they play in the lives of young people offers a valuable opportunity for digital mental health. The National Health Service has highlighted mental health apps as cost-effective and scalable solutions to barriers [9]. Existing digital mental health services, including websites and mobile apps, can offer greater and more rapid accessibility and anonymity [4] and show promise for marginalized and under-reached populations [18, 30]. Brain in Hand (BiH) is such a service. It combines 24/7 on-demand human support, and personalised coaching and digital tools to enable people to live more independently, with a particular focus on supporting the impact of executive functioning difficulties experienced by many autistic people. Research has shown that BiH is able to improve quality of life and reduce anxiety among autistic people [32] and is a good example of a digital mental health solution that can be offered at scale to people aged 16 and upwards who are diagnosed autistic or who believe they may be autistic.

A scalable product needs to be linked to scalable access. Autistic people and their supporters often look for support through internet searches and social media (BiH, unpublished data) and young people specifically use search engines to find information on mental health [25]. Searches containing the word 'Autistic' take place over 1 million times every month in the UK (BiH, unpublished data). Furthermore, digital media channels and social media are increasingly being used to reach research participants [10] and in public health campaigns [11], and evidence shows that social media is effective at targeting hard to reach groups [14] and young people aged 16–24 [10]. All the above suggests that digital media channels could be an effective approach to reach young autistic people with a service that they could self-refer to. To investigate further that hypothesis, this pilot study aimed to explore whether self-referral by autistic people to the digital mental health service, BiH, through a digital media campaign, is a feasible and effective way to reach those in need, and potentially an innovative way to improve access to a range of scalable mental health interventions.

Methods

Research design and data collection

The study used a prospective cohort design to test the feasibility and effectiveness of using digital media channels and online tools to reach and engage young autistic people as potential users of BiH. The age range of 16 to 25 was selected as this category fulfilled the research funding for SBRI healthcare "mental health challenges in children and young people". The research design, including eligibility and end-to-end self-referral pathway, was co-created with our partnering health and social care teams. To ensure suitability, young autistic people who were either current BiH users or had not previously used BiH were asked to feedback on draft, user-facing mockups of the self-referral materials and questions. Their feedback then shaped the final version used in this research.

The BiH service was offered directly to people who self-referred, without the need for a direct health or social care referral. Surrey County Council, Cheshire West and Chester Council, Devon Partnership NHS Trust, Joined Up Care Derbyshire, and the Royal Borough of Greenwich were partners in the project.

The self-referral process used several stages to reach and engage potential BiH users with the BiH service. Those who saw the digital campaign and wanted to learn more accessed the landing page. Those who remained interested after reading more about the study and BiH were then asked to complete a range of questions to assess eligibility (criteria was 16 – 25 years old, autistic (clinically diagnosed, on the waiting list, or think they might be autistic), and living in one of the five project partners catchment areas as identified by their postcode). Those not eligible were screened out. Those who were eligible were then asked to complete suitability questions (mental health needs, executive functioning challenges, and autism traits), demographic information (postcode,

ethnicity, gender identity and sexual orientation) and informed consent as part of the sign-up process. Once they had signed up, participants were sent an activation email to issue the software and get them started with BiH. They could login to access the tool and schedule a session with a BiH coach to support the participant to personalise the tool to meet their needs.

Participants and recruitment

It is unethical to target digital media campaigns to under 18's so autistic people aged 18 – 25 and the supporters of young (16 – 17 years old) autistic people were targeted via two digital marketing channels: (1) anyone searching on Google for specific search terms (i.e. autistic, autism support, support for autistic teens) within target geographical locations was presented with an advert about the study; (2) People within a specific geographical location who matched the target audience profile (age, interests, location, etc.) were shown social media (Facebook and Instagram) adverts about the study. The campaign was initiated on 19th January 2023 in Devon and closed on 7th March 2023 in Greenwich with a total of 261 people signed up. The first user signed up on the first day of the campaign (19th January) and people continued to sign up during the campaign period with the last sign up on the 5th March (2 days before the campaign closed). People could either sign themselves up directly or be signed up by their supporter. The social media campaigns for Facebook and Instagram were managed via Facebook Ads Manager and search ads were managed in Google Ads. These provided analytic data so the campaigns could be adjusted based on performance and stopped once the desired number of sign-ups was reached.

The adverts directed people to an online landing page, which explained the service offer, eligibility criteria and research project. The landing page included a simple application and consent process. People that met the eligibility criteria were able to sign up for the BiH service which was offered free of charge for one year. For 16- and 17-year-olds, their supporters were informed by email that the user had signed up to the research, along with BiH's terms and conditions. They did not need to provide additional consent but could opt out by contacting BiH's customer support team.

Reach, progress and engagement

Google analytics was used to track visits to the BiH landing page and the users' journey through the self-referral process. Reach of the campaigns was assessed by the number of times an advert was presented in search results (impressions) and how many people clicked the link to take them to the landing page. Progress was noted at stages of checking eligibility, meeting eligibility, sign up and being issued with the software. The engagement of those that were issued with software was assessed in terms of utilisation of the digital tool and the human support component (engaging with a BiH coach or on-demand support service) as of 19th May 2023 (17 weeks after the first sign-up and issue of BiH licence).

Autism traits

Participants who had not received a clinical diagnosis were asked the first 5 questions of Ritvo Autism Asperger Diagnostic Scale 14 (RAADS-14) screening tool to assess their autistic traits. The recommended cut-off score of 4 or above for the 5 questions was used to identify those who are 'likely autistic' [12, 26].

Executive functioning

A set of 8 questions (see Table 1) were developed with a group of autistic people covering the domains of self-monitoring, planning and organisation, cognitive flexibility, emotion regulation and generativity, and task initiation. They were designed to provide a snapshot of the level of executive functioning difficulties being experienced by those signing up and proved to have good internal reliability when the data was analysed (Cronbach's Alpha of 0.741). High executive functioning challenges reflects a score of 25 to 32 (out of a possible 32) and moderate challenges a score of 16 to 24.

Anxiety and depression

The Generalized Anxiety Disorder 2-item (GAD-2) [24] and the Patient Health Questionnaire 2-item (PHQ-2) [16] were used to highlight potential mental health needs among our users. A person was identified as experiencing clinically significant anxiety if they had a GAD-2 score ≥ 3 and or clinically significant depression if a PHQ-2 score ≥ 3.

Table 1 Executive functioning questions. The following 4-point scale (1 = not at all, 2 = a little bit, 3 = a lot, 4 = completely) was used to answer the question: 'how well do these statements reflect you'

Questions
I don't notice I'm tired/stressed until it's too late
I find it hard to prioritise everything I have to do
I find it difficult when things change unexpectedly
I get stuck trying to solve a problem and can't think of different approaches
I have trouble getting started on projects even if they're important to me
I tend to react without thinking first
I forget spoken instructions if they're not written down
I find it difficult to estimate how long it will take to do things

Results

Reach, progress and engagement

Reach and progress through the self-referral journey is illustrated as a Funnel Diagram in Fig. 1. The digital media campaign that lasted 6.5 weeks resulted in over 460,700 total impressions and 18,522 visits to the landing page. After processing the information on the landing page related to eligibility, service offer and participation in the study, 685 people checked their eligibility for the study, the majority of whom ($n=562$, 82%) met the criteria. Just under half ($n=261$, 46%) of eligible people signed up for the study and almost all of these ($n=243$, 93%) went on to be issued with the software by 20th March 2023 (the first licence was issued on the 20th January) and formed the final sample. Sixty-two percent of participants who were issued the software (150 young people) went on to use the service (as of 19th May 2023). The total cost of the campaign was £10,198 giving a cost per person recruited of £41.97. The cost per person would be expected to reduce if the recruitment window had been extended beyond the 6 weeks.

Participant characteristics

The 243 participants in this study were those who had chosen to sign-up for the service and had been issued with the software. The most common reason why 18 of those who signed up were not issued with software was an incorrect phone number or email address. Participants demographic characteristics are summarised in Table 2. The cohort was skewed towards the younger end of the 16–25 age range with 53% aged 16–18. Many (62%) registered female at birth, with 47% of the cohort identifying as a woman or girl. The group included 7% who identified as non-binary and 2.5% who identified as gender fluid. Of those who chose to answer, 46% identified as straight or heterosexual. The majority (93%) of the participants identified as white. Postcodes were provided by all participants and used to calculate the Index of Multiple Deprivation [20] for each individual. Approximately 7% of the participants resided in areas in the top 20% of deprivation in England. Just over half of participants signed up themselves (55%).

Autistic traits

Just over half of the participants (56%) had a clinical diagnosis of autism, with the remainder equally split between those on the waiting list (22%) and those who think they might be autistic (22%) (see Table 2). The first 5 items of the RAADS-14 indicated high levels of autism traits among those who had not been formally diagnosed. Using a cut-off score of 4 or above identified that 95% of this group were likely autistic.

Level of need

Levels of anxiety and depression were high, 83% scored in the clinically significant range of the GAD-2 and 69% scored in the clinically significant range of the PHQ-2 (see Table 2). Most participants (99%) indicated they

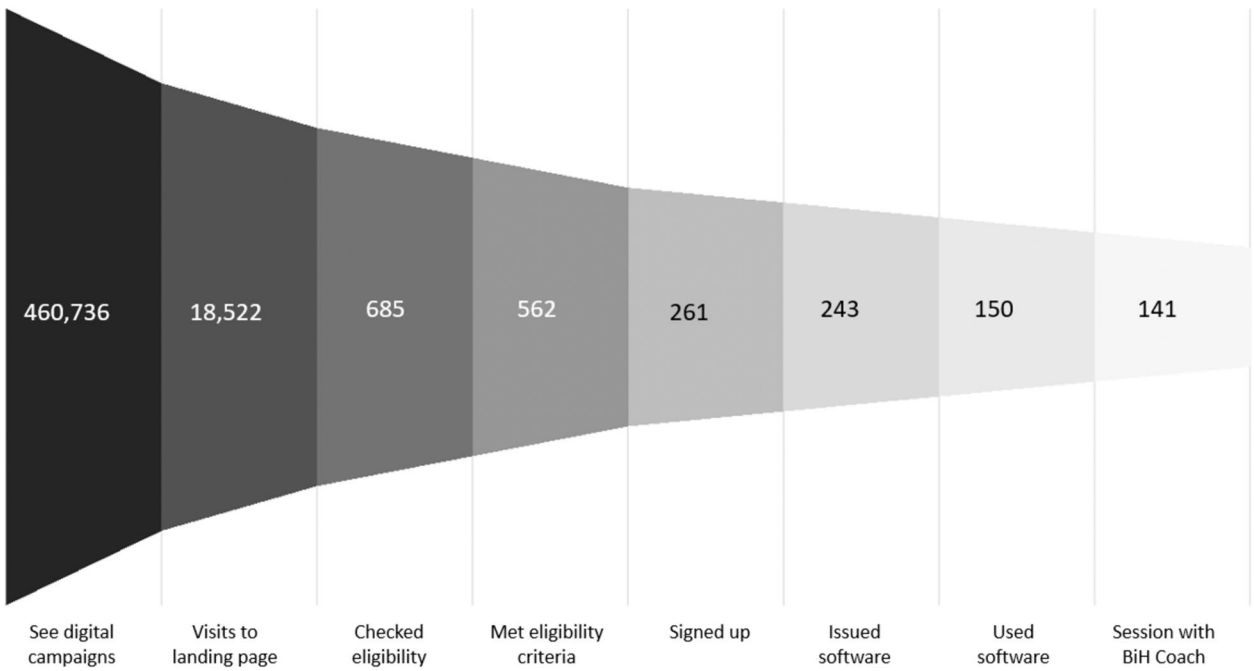

Fig. 1 Funnel chart depicting numbers at each stage of the self-referral journey

Table 2 Participant demographics characteristics and needs ($n = 243$)

		Sample size	Percentage
Age	16-17	89	36.6%
	18-21	94	38.7%
	22-26	60	24.7%
Diagnosis	Clinically diagnosed as autistic	137	56.4%
	On the waiting list for autism assessment	52	21.4%
	Think they might be autistic	54	22.2%
Referred by	Referred by self	134	55.1%
	Referred by supporter	109	44.9%
Assigned sex at birth	Female	150	62.0%
	Male	88	36.3%
	Prefer not to say	4	1.7%
	Did not respond	1	-
Sexual orientation	Heterosexual / straight	105	43.4%
	Don't know	36	14.9%
	Bisexual	33	13.6%
	Gay / Lesbian	24	9.9%
	Pansexual	17	7.0%
	Asexual	10	4.1%
	Prefer to self-describe	5	2.1%
	Prefer not to say	12	5.0%
	Did not respond	1	-
Gender identity	Woman/girl	113	46.7%
	Man/boy	84	34.7%
	Non-binary	16	6.6%
	Gender fluid	6	2.5%
	Trans man/boy	4	1.7%
	Trans woman/girl	2	0.8%
	Gender queer	1	0.4%
	Prefer to self-describe	2	0.8%
	Prefer not to say	8	3.3%
	Don't know	6	2.5%
	Did not respond	1	-
Ethnicity	White: English/Welsh/Scottish /Northern Irish /British	212	87.6%[a]
	White: Other white background	10	4.1%
	Mixed Ethnicity: White and Black Caribbean	5	2.1%
	Mixed Ethnicity: White and Asian	3	1.2%
	White: Irish	2	0.8%
	Arab	1	0.4%
	Black: African	1	0.4%
	Black: Caribbean	1	0.4%
	Other	3	1.2%
	Prefer not to say	3	1.2%
	Don't know	1	0.4%
	Did not respond	1	-
RAADS Categories (asked of the 106 who did not have a clinical diagnosis)	Likely Autistic	96	95.0%
	Not Likely Autistic	5	5.0%
	Did not respond	5	-

Table 2 (continued)

		Sample size	Percentage
Executive Functioning Categories	High Executive Functioning Challenges	141	58.0%
	Medium Executive function Challenges	99	40.8%
	Low Executive Functioning Challenges	3	1.2%
Clinically significant anxiety symptoms (GAD2 score > or =3)	Clinically significant	201	82.7%
	Not clinically significant	42	17.3%
Clinically significant depression symptoms (PHQ2 score > or =3)	Clinically significant	167	68.7%
	Not clinically significant	76	31.3%
Current Support	Currently receiving support	98	40.3%
	No current Support	145	59.7%
Past Support	Received services in past	182	74.9%
	No past services	61	25.1%

[a] Total percentage is 99.8% due to rounding errors and small numbers in disaggregated sub-group

were experiencing moderate (41%) or high (58%) levels of executive functioning challenges. Three quarters of participants had received support services in the past, but only 40% were receiving some form of support service at the time of the project.

Discussion

We found that a diverse group of young autistic people could be reached using digital media campaigns with close to half a million people viewing the adverts and nearly 20,000 visiting the landing page over 6.5 weeks. Furthermore, our final group of 243 eligible participants who had been issued with BiH software demonstrated high levels of need in terms of anxiety, depression and executive function and were suitable for support by the BiH service. They were also highly motivated with 150 (62%) already actively using the support tool within 2 months of the licence being issued. This compares favourably with retention rates for many digital mental health apps which typically fall below 10% by 30 days [2]. The overall findings of this study represent a powerful example of how self-referral and digital media campaigns can efficiently and effectively provide access to a digital tool for those who need support. This self-referral approach engaged young people with clinically significant levels of anxiety and depression (more than two-thirds of the participants) and moderate and high levels of executive functioning challenges in nearly all (99%).

As a population, autistic people experience poorer health outcomes compared to their neurotypical peers – reduced life expectancy, elevated risk of suicide and high prevalence of mental health difficulties [8, 23]. These disparities can be further exacerbated by other factors such as living in deprived areas, belonging to an ethnic minority, or being LGBTQ+, and further compounded by intersectionality as many of these social identities overlap. Often those with elevated risk of health disparities who fall into these categories are described as 'under-reached' and are less likely to engage with services when offered [20]. The government's strategy for tackling healthcare inequalities is set out in the Core20PLUS5 framework and identifies children and young people (CYP) most at risk of health inequity as being the most deprived 20% of the population, those with certain protected characteristics (including gender, race/ethnicity, autism, LGBTQ+) and those with specific needs, including mental health needs [19]. The digital media campaigns were successful at reaching the LGBTQ+community. Participants were richly diverse compared to the general population [21]. For example, Trans representation at 2.4% was much higher than the 0.3% in the general population with all other gender identities accounting for 9.5% of our participants compared with only 0.6% in the general population.

The challenge came in reaching minority ethnic groups with most of our participants identifying as white. Underpinning the Core20PLUS5 framework is evidence that CYP from ethnic minority backgrounds are less likely to access services around early intervention to prevent mental health problems escalating, and recent research has shown that most minoritised ethnic groups are offered and receive psychological interventions in Early Intervention in Psychosis (EIP) less often than White British people [29]. There is also evidence of ethnic disparities in the diagnosis of autism, with children from minority ethnic groups being diagnosed with autism later and at a lower rate when compared to white children [27], possibly resulting in lower awareness in these communities [15]. Data and digital poverty are also more prevalent among ethnic minorities [1]. While there were obvious challenges in reaching ethnic minority

groups with this approach, it is not clear whether this was a result of access to digital media and tools or related to awareness and acceptance of neurodiversity and its mental health impacts, or a combination of both.

Although the approach piloted here is of obvious interest to those implementing a public health approach to early intervention and prevention in the autistic population, the findings are also relevant more widely to other underserved populations whose needs could be met with digital solutions. We have shown that there is the potential to deliver services differently. In the short time window of fewer than 9 weeks, digital media campaigns resulted in 243 autistic people being issued the licence for BiH at a recruitment cost of less than £50 per person. The recruitment window closed as we reached our licence limit for the study, but an extension of the recruitment window could have made this even more cost-effective.

Strengths and limitations

This study used only two digital media channels to reach participants, Meta (Facebook and Instagram) and google search, and future work could benefit from examining other popular digital media channels. Although the age range for participation was 16–25 years, 53% were aged between 16 to 18 years which may limit the generalisability of the findings for young people in the older age range. Furthermore, the exclusion of people older than 25 years may have influenced the applicability of this approach for older autistic people given possible age-related digital competence and support needs. In addition, few people came from minority ethnic groups and more investment should be put into understanding how better to reach these communities. Although a 1.3% conversion rate to sign up could be considered low, many going to the landing page may not have been suitable for BiH. The self-referral materials used in the research were effective at helping potential users to understand whether or not BiH is suitable for them and this learning could help inform the initial media messages in future digital campaigns. Finally, the use of self-reported executive problems has been called into question as an accurate measure of performance based neuropsychological executive function for some conditions [33] although the high levels of anxiety and depression are strongly suggestive of need, even after acknowledging that the former can also overlap with the latter as expressions of co-occurring emotional difficulties.

Conclusion

The current structure and capacity of the health and social care system is unable to manage the growing levels of need for support in the autistic population. Innovation is urgently needed not only in the interventions that are offered to support greater independence but also in the way that support is offered. This study shows that a direct to person approach is both a feasible and effective way of reaching and engaging a high need population. When coupled with an effective digital mental health solution, the potential for impact at scale, including within under-reached communities, is considerable.

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Authors' contributions

Authors ND and LM initially conceptualised the research study. ZS led on the study design and data collection with support from ND, JL and LM. JL led on the development of the eight executive function questions. ZS, ND and HG performed the data analysis, data interpretation, and generation of figures and tables. HG prepared the manuscript. All authors reviewed and approved the final manuscript.

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Data availability

The individual record data contains personal information on participants characteristics which when taken together could lead to their identification and links to sensitive data. For this reason only the aggregated data is provided in the manuscript.

Declarations

Ethics approval and consent to participate

REC approval was received from Lab Research Ethics Panel (LabREP) (CSP-BiH-020923). The Ethical Committee is comprised of fellows of the Centre for Social Policy and provides ethical oversight and approval to the Warren House Group at Dartington, a charity undertaking research and development in child welfare. The committee is chaired by Roger Bullock, who is Emeritus Professor of Child Welfare Research, Bristol University. Informed consent to participate in the evaluation was obtained online from all participants at sign up, immediately following consent for service use.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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