

The psychological and social impact of the digital self-support system “Brain in Hand” on autistic people

Samuel Tromans

Associate Professor of Psychiatry
And Honorary Consultant Psychiatrist
Faculty of Psychiatry of Intellectual
Disability Spring Conference: 28th April 2023



Leicestershire Partnership 
NHS Trust



Contents

- Background
- Methodology
- Results
- Discussion

Background



- **Autism is a lifelong neurodevelopmental condition, characterised by atypicalities in social communication and interaction**
 - And a pattern of restricted, repetitive and stereotyped behaviours (American Psychiatric Association, 2013)
- **Approximately 0.8% of the general population are autistic** (Brugha et al, 2011)
 - With heightened prevalence in adults using both inpatient and community mental health services (Brugha et al, 2020)
- **Autistic people are at heightened risk of mental illness relative to their non-autistic peers**
 - **Lai et al. (2019)**
 - Anxiety disorders (20%; 95% CI = 17-23)
 - Depressive disorders (11%; 95% CI = 9-13)

Background



- **Considerable interest in digital interventions for supporting autistic people**
(Sandgreen et al, 2021)
 - Reduced social demands relative to in-person approaches? (Golan et al, 2006)
- **Most previous research has focussed on autistic children**
- **Brain in Hand is a combination of digital health solutions**
 - Designed to support self-management and foster independence
 - Not designed specifically for autistic people
 - But has been used previously in both autistic and mental health groups

Brain in Hand Walkthrough



braininhand

Aim

- **To ascertain the strengths and limitations of Brain in Hand**
 - With respect to mental health and social functioning for adults with diagnosed or suspected DSM-5 level 1 autism



What is DSM-5 Level 1 Autism?



- **'Requiring support'**
 - Lowest of three severity levels
 - Level 2: 'Requiring substantial support'
 - Level 3: 'Requiring very substantial support'
- **Social communication**
 - Significant impairment without support
 - Difficulty initiating interaction and responding to social overtures
 - Could appear to have reduced interest in social interaction
- **Restricted, repetitive behaviours**
 - Inflexibility causing significant impact in ≥ 1 contexts
 - Difficulties in activity switching, organisation, and planning

Methodology: Study Design



- **Mixed methods cohort design**
 - Both quantitative and qualitative approaches were required to address study objectives
- **Quantitative measures (Baseline and 12-weeks post-intervention)**
 - Hospital Anxiety and Depression Scale (HADS) (Zigmond et al, 1983)
 - Health of the Nation Outcome Scale for People with Learning Disabilities (HoNOS-LD) (Roy et al, 2002)
- **Qualitative component**
 - Semi-structured interviews of a sample of participants who finished the study
 - Thematic analysis, using process described by Braun and Clarke (Braun and Clarke, 2006)

Methodology: Participants



- **Purposive sampling approach**
 - Clinical care teams accessed potential participants via:
 - Medical records
 - Autism diagnostic service waiting lists
- **Quantitative sample: Target of 100 participants**
 - Allowing for required statistical power with a 10% drop-out rate
 - 80% at 0.05 significance level
 - Based on detecting a standardised effect size of 0.3 for change in HADS score
- **Qualitative sample: 10 participants**
 - All drawn from the quantitative sample

Methodology: Inclusion and Exclusion Criteria

Inclusion	Exclusion
Level 1 DSM-5 autism diagnosis, or post screening by a health professional and on the autism diagnostic pathway.	Any acute or chronic condition, particularly neurodevelopmental conditions such as significant intellectual disability, or Level 2/3 DSM-5 autism.
Aged 19 to 80 years.	<19 or >80 years of age.
Screened by the Columbia Suicide Severity Rating Scale (C-SSRS) (Posner et al, 2008) as not having risk concerns of suicide.	Screening positive with the C-SSRS.
Access to smart devices with compatibility to running BIH, such as mobile smartphones, tablet devices and laptop computers.	Unwilling to engage with a smart device/ the internet.
Capacity to give informed consent for study participation.	Declining or unable to give informed consent.
	Suspected or clinically diagnosed co-occurring mental health conditions (psychosis, severe depression etc.) that would limit the ability of the participant to take part.
	Insufficient English language to understand and complete questionnaires.

Methodology: Patient and Public Involvement

- **Study documents developed in collaboration with an accessibility team**
 - Including members with lived experience of autism
- **Autistic people examined the study design and ensured interview questions were accessible**
- **Brain in Hand had an independent user panel with 14 autistic members**
 - Involved in development of Brain in Hand
 - Provided study oversight



Methodology: Analysis



- **Association between demographic characteristics and autism diagnostic status**
 - Fisher's exact test
- **Effectiveness of Brain in Hand according to mean outcome scores**
 - Paired t-test
 - Bonferroni correction applied for HoNOS-LD analyses
 - i.e., p -value threshold set at <0.003 to account for multiple testing
- **Ascertaining whether changes in outcome scores were associated with demographic characteristics**
 - Multivariable linear regression
- **Comparison of demographic and baseline characteristics with risk of drop-out**
 - Logistic regression

Methodology: Further Details

- **Funded by the NHS England Small Business Research Initiative**
- **Approved by NHS Research Ethics Committee**
 - Reference 21/SW/0066
- **Registered on Clinicaltrials.gov**
 - Reference NCT05468541
- **Recruitment took place across 7 NHS healthcare trusts in England and Wales**
 - Total catchment population of approximately 7 million



Results: Study Population (Quantitative)

Variable	Waiting list (n = 47)	Autism diagnosis (n = 52)	Overall (n = 99)	P-value
Gender				
Male	13	15	28	
Female	33	34	67	
Other	1	3	4	
Age group				0.67
19-30	19	20	39	
31-40	11	13	24	
41-50	5	5	10	
51-60	10	9	19	
61-80	1	5	6	
Missing	1	0	1	
Employment status				0.85
Employed	21	26	47	
Unemployed	19	19	38	
Other	7	7	14	
Support				1.00
Supported	15	17	32	
Not supported	30	32	62	
Other	2	3	5	
Accommodation				0.31
Own home	20	17	37	
Rented	21	31	52	
Other	6	4	10	
Relationship status				0.90
Married/partner	25	25	50	
Divorced	3	3	6	
Single	18	22	40	
Not known	1	2	3	

Results: Study Drop-Out

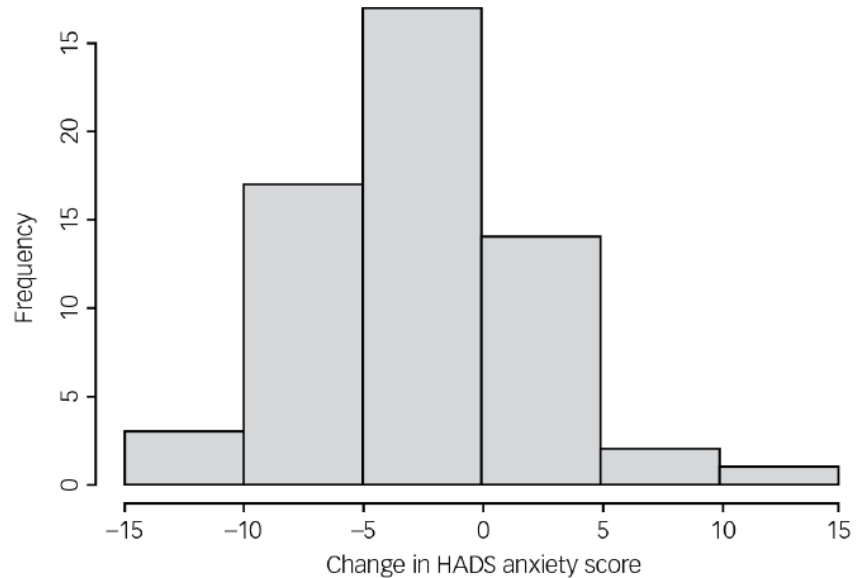
- **33% of the study population ($n = 33$) dropped out**
 - **Associated factors:**
 - Aged 31-60 years
 - Living in rented/other accommodation
 - Low baseline HADS anxiety score

Variable	<i>n</i>	Odds ratio	<i>p</i>
Age, years	19-30	39	Reference
	31-40	24	3.68 (1.00-14.53) 0.054
	41-50	10	3.48 (0.60-20.88) 0.160
	51-60	19	3.79 (0.85-18.65) 0.088
	61-80	6	1.33 (0.12-11.40) 0.796
Accommodation	Own home	37	Reference
	Other	9	8.75 (1.30-65.07) 0.028
	Rented	52	4.12 (1.36-14.06) 0.017
HADS anxiety	98	0.41 (0.23-0.68) 0.001	

0.2 0.2 1 2 5 10 20 50

Results: Quantitative Findings

- **Baseline and follow-up HADS were completed by 66 participants**
 - **Significant reduction in HADS anxiety scores**
 - Mean reduction = -2.2
 - $p = 0.0004$
 - 95% CI = -3.43 to -1.04
 - **Absence of a significant reduction in HADS depression scores**
 - mean reduction = -0.59
 - $p = 0.31$
 - 95% CI = -1.75 to +0.56



Results: Quantitative Findings

- **Baseline and follow-up HoNOS-LD were completed by 64 participants**
 - **Significant reduction in total HoNOS-LD score (improved functioning)**
 - Mean reduction = -5.7
 - $p = <0.001$
 - 95% CI = -7.5 to -3.5
 - **Significant reductions ($p<0.003$) observed across multiple HoNOS-LD clusters and domains**

Item Cluster	Baseline median	Follow-up median	<i>p</i> -value
Behavioural problems (items 1-3)	5.0	3.5	0.001
Cognition (items 4-5)	2.0	1.5	0.003
Communication (items 6-7)	2.0	1.0	0.001
Mental state (items 8-11)	4.0	4.0	<0.001
Physical problems (items 12-13)	0.0	0.0	0.61
Activities of daily living (items 14-16)	3.0	2.0	0.01
Social functioning (items 17-18)	2.0	1.0	<0.001

Results: Quantitative Findings

HONOS-LD Item	Baseline mean	Follow-up mean	p-value
1. Behaviour towards others	0.89	0.85	0.37
2. Self-injurious behaviour	1.30	0.58	<0.001
3. Other mental and behavioural problems	1.57	1.42	0.16
4. Attention and concentration	1.25	1.05	0.08
5. Memory and orientation	0.88	0.47	<0.001
6. Communication problems in understanding	1.00	0.39	<0.001
7. Communication problems in expression	0.86	0.59	0.02
8. Hallucinations and delusions	0.09	0.08	1.00
9. Mood changes	1.63	1.38	0.02
10. Sleep problems	1.66	1.39	0.04
11. Problems with eating and drinking	1.04	0.68	<0.001
12. Physical problems	0.62	0.62	0.73
13. Seizures	0.07	0.06	0.37
14. ADL at home	1.18	0.94	0.11
15. ADL outside home	1.22	1.05	0.04
16. Level of self-care	0.86	0.71	0.16
17. Problems with relationships	1.53	0.89	<0.001
18. Occupation and activities	1.12	0.74	<0.001

Results: Study Population (Qualitative)

- All participants randomly selected for interview consented
- Thematic analysis was conducted
 - Data saturation was achieved




Variable	<i>n</i>
Status at time of study participation	
Confirmed autism diagnosis	5
Waiting list	5
Gender	
Male	4
Female	6
Age group	
19-30	5
31-40	3
41-50	1
51-60	1
Employment status	
Employed	7
Unemployed	2
Other	1
Support	
Supported	5
Not supported	5
Accommodation	
Own home	3
Rented	6
Other	1
Relationship status	
Married/partner	6
Single	4

Results: Qualitative Findings



- **Brain in Hand set-up process ('on-boarding')**
 - Participants expressed positive views
 - Particularly when specialist reported being autistic themselves
 - Lack of flexibility regarding process
 - E.g., Some participants had significant IT ability
- **Building confidence**
 - Participants reported Brain in Hand having a positive impact on their confidence
 - The relationship with their specialist was emphasised

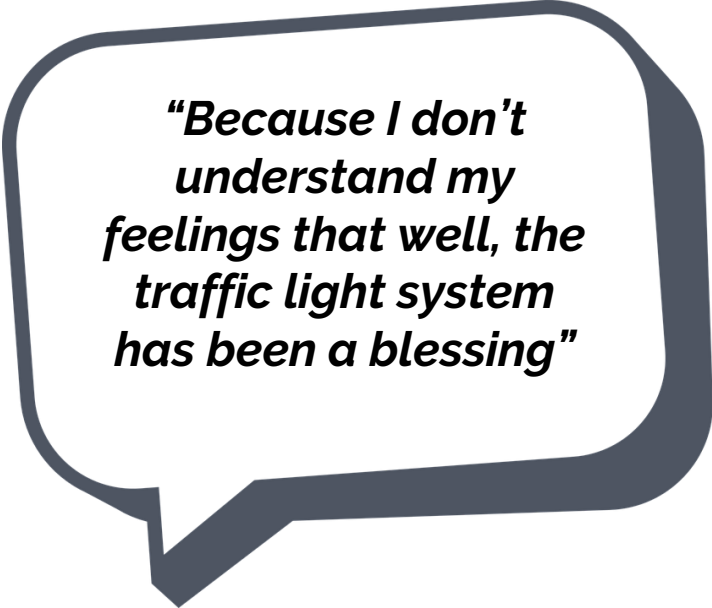


“At supermarkets where I get overwhelmed, for example, even if I didn’t use it, it just gave me that little bit of extra confidence I think”

Results: Qualitative Findings




- **Traffic-light system and self-awareness**
 - Participants felt the traffic light tool supported their own emotional awareness
 - And prevent escalation of sensory overload
- **Suggested developments**
 - Personalisation for on-boarding
 - Improved synchronisation with other apps
 - Increased user-user peer support
 - Inclusion of strategy bank for users
 - Immediate website access



“Because I don’t understand my feelings that well, the traffic light system has been a blessing”

Results: Qualitative Findings

- **Recommending to other autistic people**
 - All interview participants would recommend Brain in Hand
 - Commitment required during on-boarding
 - Considered an addition to (rather than a substitute for) current care
- **COVID-19 and experience of isolation**
 - Some participants expressed positive views regarding lockdown
 - E.g., A reprieve from usual social obligations



“I didn’t particularly mind being inside. It was more when we started to go out again that the anxiety hit”

Discussion



- **Patients using Brain in Hand for 12 weeks reported a significant improvement in self-reported health and social functioning**
 - As measured by HoNOS-LD
 - And significant reduction in multiple HoNOS-LD items
 - Including self-injurious behaviours
- **A significant reduction in self-reported anxiety was observed**
 - With no concurrent significant reduction in self-reported depressive symptoms
- **Semi-structured interview participants reported improved functioning and confidence from using Brain in Hand**

Discussion: Strengths



- **Generalisability**
 - The study cohort was recruited from multiple sites across England and Wales
- **Involvement of autistic people**
 - In development of Brain in Hand and the study itself
- **Mixed-methods design**
 - Enabling a richer quality of data collection

Discussion: Limitations



- **Relatively small sample size**
 - Underpowered quantitative sample due to high drop-out rate
 - **Lack of active case finding**
 - Findings not generalisable to undiagnosed and diagnosed autistic adults
 - **Lack of non-autistic participant group**
 - Unclear whether effects of Brain in Hand are autism-specific
 - **Lack of randomised control group**
 - i.e., Lack of comparison with treatment as usual
 - **No ethnicity and education data collected from study population**
 - **Study duration of 12 weeks**
 - Unclear whether effects would be sustained for a longer period
-

Discussion: Implications



- **Clinical**

- Brain in Hand has demonstrated effectiveness in improving health and social functioning of autistic adults
- As well as reducing self-reported anxiety symptoms and self-harming behaviours
- No significant adverse effects were reported

- **Research**

- Research needed to establish impact over longer time periods
 - And in other adult groups, such as those with mental illness

- **Policy**

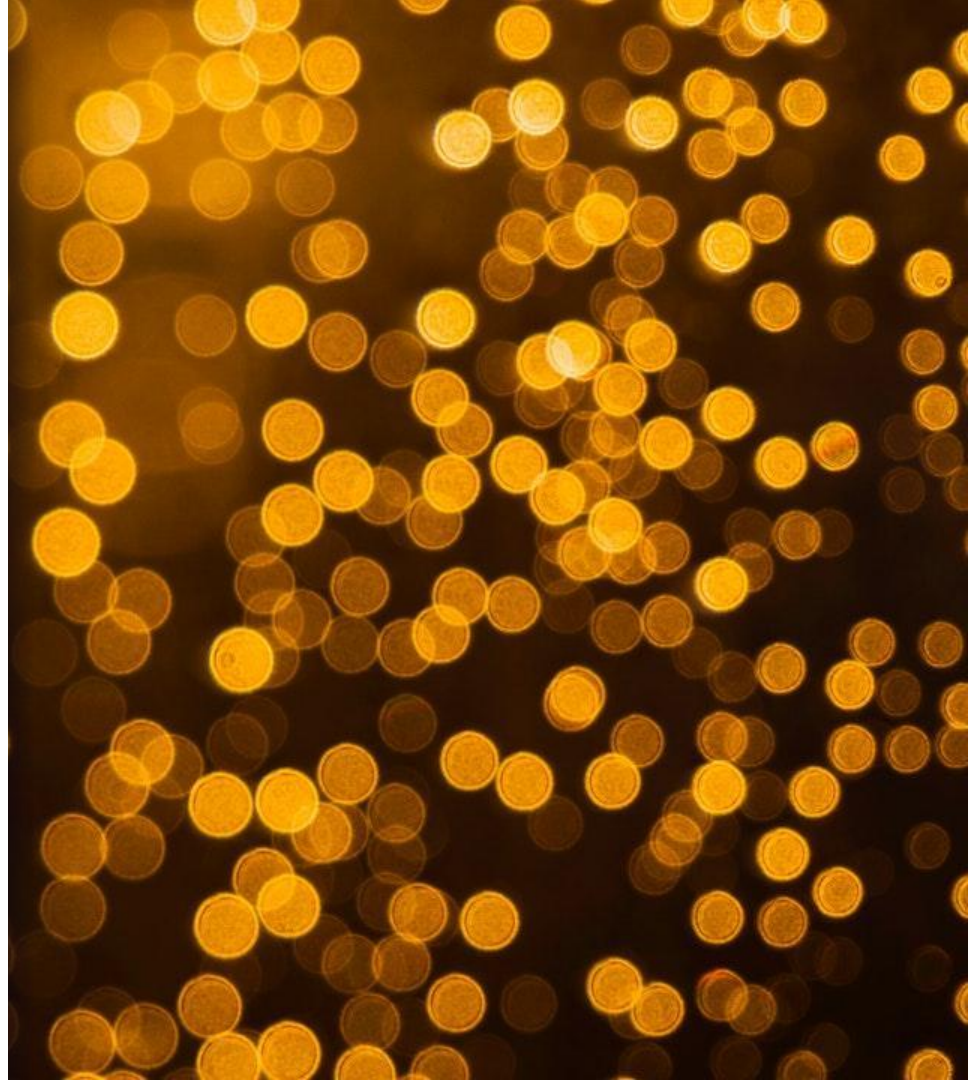
- Brain in Hand meets research standards for Tier C of the NICE Digital Technologies framework (NICE, 2019)
- Needs to be subjected to robust economic evaluation

References

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. *Arlington: American Psychiatric Publishing* 2013.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology* 2006;3:77-101.
- Brugha TS, McManus S, Bankart J, et al. Epidemiology of autism spectrum disorders in adults in the community in England. *Arch Gen Psychiatry* 2011;68:459-65.
- Brugha T, Tyrer F, Leaver A, et al. Testing adults by questionnaire for social and communication disorders, including autism spectrum disorders, in an adult mental health service population. *International Journal of Methods in Psychiatric Research* 2020:e1814.
- Golan O, Baron-Cohen S. Systemizing empathy: Teaching adults with Asperger syndrome or high-functioning autism to recognize complex emotions using interactive multimedia. *Dev Psychopathol* 2006;18:591-617.
- Lai M, Kassee C, Besney R, et al. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry* 2019;6:819-29.
- NICE. Evidence Standards Framework for Digital Health Technologies: March 2019. <https://www.nice.org.uk/Media/Default/About/what-we-do/our-programmes/evidence-standards-framework/digital-evidence-standards-framework.pdf>.
- Posner K, Brent D, Lucas C, et al. Columbia-suicide severity rating scale (C-SSRS). *New York, NY: Columbia University Medical Center* 2008;10.
- Roy A, Matthews H, Clifford P, et al. Health of the nation outcome scales for people with learning disabilities (HoNOS-LD). *The British Journal of Psychiatry* 2002;180:61-6.
- Sandgreen H, Frederiksen LH, Bilenberg N. Digital interventions for autism spectrum disorder: a meta-analysis. *J Autism Dev Disord* 2021;51:3138-52.
- Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67:361-70.

Acknowledgements

- **Cornwall Partnership NHS Trust and Cornwall Intellectual Disability Equitable Research – University of Plymouth:** Rohit Shankar, Richard Laugharne, Ian Summers, Danielle Bilkey, Jenna Datson
- **Cornwall Partnership NHS Trust:** Rebecca Jelbert
- **University of Exeter Medical School:** William Henley
- **Brain in Hand Limited:** Louise Morpeth, Nicola Doherty, Sarah Benbow
- **Coventry and Warwickshire Partnership NHS Trust:** Ashok Roy
- **University of South Wales and Swansea University Health Board:** Lance Watkins
- **Barnet, Enfield, and Haringey Mental Health NHS Trust:** Bhathika Perera
- **Cheshire and Wirral Partnership NHS Foundation Trust:** Saman Shazad
- **Devon Partnership NHS Trust:** Richard Pender
- **Herfordshire Partnership University NHS Foundation Trust and University of Hertfordshire:** Regi Alexander
- **NIHR Clinical Research Network (Portfolio Support)**
- **NHS Small Business Research Initiative (Funding)**
- **Study participants**
- **Slidescarnival.com (Presentation Slide Design)**



Thank you. Any questions?

- st386@leicester.ac.uk



- Article currently in press:

BJPsych
open

