Helptech for Students with Autism

A National Autistic Society pilot trial funded by The Department of Health

“it has increased independence in that I’m not asking other people to help me, I’m helping myself because I am looking at Brain in Hand”
Summary

Brain in Hand is an assistive technology for people on the autism spectrum. The National Autistic Society (NAS) ran a small trial of Brain in Hand as part its support for Higher Education students in London. The results were encouraging; overall 53% of students rated the impact of Brain in Hand to be positive or extremely positive, the same number felt more able to implement strategies and half reported feeling more confident.

Key insights for onward improvement are the effective screening of users alongside thorough set up and consistent training of both mentors and users. This trial and its insights have directly informed the development of a dedicated Brain in Hand student service and the NAS has now partnered with Brain in Hand to provide the facilitator (red-button response) aspect of this service.

Brain in Hand is now available to students on the autism spectrum at universities across the UK through the Disabled Students Allowance, so there is potential for its impact to be studied on a larger scale.

Introduction

More and more people on the autism spectrum are entering Higher Education. The Higher Education Statistical Agency recorded over 2,400 students with ‘autism spectrum conditions’ in UK universities in 2013-14, a 300% rise in three years. This dramatic growth requires appropriate support and adjustments for autistic students to really thrive.

For young adults, moving from further education to university can be overwhelming and worrying. The National Audit Office states ‘university is a major step for young people’ and ‘without appropriate support people with autism may not fulfil their potential and complete their degree’ (Supporting people with autism through adulthood, NAO, 2009).

The NAS is the UK’s leading charity for people on the autism spectrum (including Asperger syndrome) and their families providing information, support and pioneering services to over 100,000 people every year.

The NAS Student Support Service provides specialist mentors for students with an autism diagnosis to support them with various aspects of university life. The mentor meets the student regularly to develop strategies; for example around managing workload, or coping with change. However, at times of high anxiety, students may find it difficult to access and implement these strategies. In addition, people on the autism spectrum often have difficulties with communication, and identifying and describing their feelings in weekly mentoring sessions can be difficult, particularly if the situation that caused anxiety has passed.

Brain in Hand is a web-based mobile assistive technology. It uses a secure, cloud-based service that synchronises with a smartphone or tablet, giving students access to their coping strategies when they need them, and allowing them to report their mood and feelings. The key features are:

• A diary feature creates a structured routine and ‘recipes’ for difficult-to-remember tasks.
• Users can build pre-planned coping strategies into the system to help them deal with difficult situations. These strategies are instantly accessible in a simple format on their smartphone.
• A traffic light system alerts a facilitator when a user reports high anxiety, enabling a timely intervention.
• Data is recorded in real time and displayed on a timeline allowing users and support team members to track and understand situations or issues.

Aim

A trial was set up to explore how well Brain in Hand enhanced the NAS’s mentoring service for Higher Education students on the autism spectrum. The trial was sponsored by the Department of Health.

Method

The NAS Student Support Service in London supports over 100 students across all academic years. Twenty-four students volunteered to take part in the trial: 14 males and 10 females, aged from 20 to 34, spread across three academic years and seven London universities.

All participants had smartphones and were trained in how to use Brain in Hand to develop personalised coping strategies for planned and unplanned situations as well as how to use the ‘traffic light’ system to register ‘red’, ‘amber’ or ‘green’ anxiety levels.

Student Support Service mentors were given one day of training plus two refresher sessions. Data was stored and accessible on each student’s secure website which could then be used to feed into scheduled one-to-one sessions. The trial ran during the second and third terms of the academic year (January to June 2015).

Students were asked to complete a questionnaire before and after the trial. At the end of the trial they were also asked a series of direct questions about the impact of Brain in Hand. Finally, semi-structured interviews were used to collect feedback. Five students dropped out as they either discontinued their studies, or felt anxious about the study’s short duration. Sixteen students completed the post-trial questionnaire.

Results

Overall 53% of students rated the impact of Brain in Hand to be positive or extremely positive.

“It has made me realise alternative ways of managing problems For example, when I go out, I remember what to take with me to keep myself calm, and what to do if I get panicky.”

“If I’m stressed and I can’t think straight I look at BIH. BIH refreshes my memory to remind me what strategies to use.”

“Looking at BIH is much easier than asking a person for help, as communication is often hard for autistics”

This section uses student quotes from the structured interviews to illustrate some of the specific areas of help.
Anxiety

At the start of the trial every student agreed that “I feel anxious often”. After the trial one in three students no longer said they did. This reduction of over 30% met the criteria set at the beginning of the study and is a statistically significant reduction.

“When I’m anxious or having a meltdown I can’t think logically. I pick up BIH and it triggers off good strategies that I wouldn’t think of otherwise. It reminds me of how to cope.”
“I cope now with exam stress, revision and interaction with students.”
“Very helpful in terms of recording how you are feeling.”

Time management

Seven of the sixteen students said they were more able to manage their time at university as a result of Brain in Hand; six said the same regarding their time outside of university. Five said they were better able to manage their workload.

“It’s helped set a plan and time management for my uni work and easy access to inform a specialist if I’m in distress.”
“I have managed being more busy than normal without getting extremely anxious.”

Confidence and Independence

Eight out of sixteen said they were better able to cope when things don’t go according to plan and better able to implement strategies discussed with their mentor. Six agreed that ‘as a result of using Brain in Hand’ they were better able to cope with change and were more confident in general. Seven were more confident in using communication skills.

Seven students said that they were more engaged in their course, and six said they felt more optimistic about the future.

“It has given the independence to actually be independent and do things by myself.”
“It has helped me concentrate in lectures as it is quick to use and I can glance at it.”
“I’ve found it a pretty good experience really, as an assistive technology it was really useful.”
“I wish something had been available when I was younger.”

Discussion & Recommendations

The results were encouraging especially in terms of improving confidence and controlling anxiety. Some students were better able to manage their time and implement strategies from their mentor sessions. They also became more confident in using strategies when things don’t go to plan, and as a result felt engaged with their course and optimistic for the future.

Feedback from students and mentors suggests that Brain in Hand is a useful tool for reflecting on anxiety, both for the student independently as well as with their mentor in one-to-one sessions. By reviewing their timeline, and examining what caused the anxiety or stress, students could discuss issues and input strategies for overcoming those challenges directly into their Brain in Hand. When a student encountered a difficult situation they could then access reminders of their best thinking and plans available on their phone when they need it most.
Students also reported that Brain in Hand promoted independence by providing a discreet, non-stigmatising way of asking someone for answers or support. This element of the system forms a ‘safety net’ for the students where the red button responder can remind the students of the strategies on their Brain in Hand and, once resolved, suggest that the student inputs new coping strategies for that situation should it occur again.

This was a relatively short, small trial and, without a control group, it is possible that some of the impact of Brain in Hand was due to other factors such as students generally becoming used to university life.

Finally, students varied greatly in their use and application of Brain in Hand. It was beneficial for some students with autism whose way of thinking was in line with the technology but it was not useful for all students.

Recommendations

1. Encourage students to use Brain In Hand from the start of the academic year.
2. Check that students are interested or familiar with technology.
3. Give both the users and support staff full training.
4. Offer refresher training, since people learn at different speeds.
5. Improve certain specific Brain In Hand’s features (see table below)
6. Consider a longer, larger scale trial with a control group

Developments for the service

The Brain in Hand student service has responded to this feedback by creating guidance for student assessment to help identify those for whom it will be most beneficial. Training is available for students and supporters. The facilitation service (red button response) run by the National Autistic Society is designed to help students’ use stabilise and improve throughout the first year of their course, to make sure they get the best out of the system. The system itself has also been updated in response to their comments on features.

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<tr>
<th>Feedback</th>
<th>Response</th>
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<td>The traffic lights function was seen as particularly effective at monitoring moods allowing students to reflect on their anxiety levels, giving them the reassurance that a helpline responder was there if required.</td>
<td>We have now introduced ‘mentor affinity’ where the red button responder can be ‘flipped’ over in the evenings, weekends or holidays.</td>
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<td>Certain aspects of the diary feature were highlighted for development as students wanted to more functionality and ease of use.</td>
<td>We have introduced a reminders feature to the diary allowing students better prepare for and manage their day.</td>
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<td>The unplanned was seen as valuable because it allowed students to bring structure to dealing with problems that don’t fit into a neat schedule.</td>
<td>We are developing a check list function to enhance the unplanned page which is due for release in the next six months.</td>
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