

Pirate adventure autism assessment app: a new tool to aid clinical assessment of children with possible autistic spectrum disorder

E Jordan¹, W J Farr^{1,2}, S Fager³, I Male^{1,2}

¹Brighton and Sussex Medical School, University of Sussex,
Brighton, UNITED KINGDOM

²Mid Sussex Child Development Team, Sussex Community NHS Foundation Trust
Butlers Green Rd, Haywards Heath, W Sussex, UNITED KINGDOM

³Cell Software Services,
Frederick Terrace, Brighton, UNITED KINGDOM

E.Jordan1@uni.bsms.ac.uk; ian.male@nhs.net, will.farr@nhs.net, stefan.fager@cellsoftware.co.uk

¹*www.bsms.ac.uk, www.sussexcommunity.nhs.uk, cellsoftware.co.uk*

ABSTRACT

Diagnostic assessment of possible Autistic Spectrum Disorder requires multidisciplinary assessment incorporating information from various settings, including psychometric assessment of the child. The Pirate Adventure Autism Assessment App includes a number of these psychometric tests adapted into a pirate adventure storyline. Early experience, presented here, suggests the tool is a useful adjunct to parental history and school questionnaire obtained at initial clinic, in determining the need for the child to proceed to a full, time consuming, expensive, diagnostic assessment.

1. INTRODUCTION

Autistic Spectrum Disorders (ASD) affect at least 1.1 % of the population (CDC, 2014) and maybe even twice this figure with the possibility of under-representation in females. In the absence of a blood test, X-ray, or other scan that can confirm diagnosis, a multidisciplinary process is recommended in the UK requiring information from various sources including home and educational setting, as well as observation and testing for evidence of autistic behaviours and/or patterns of thinking (NICE, 2011). A number of tools have been developed to aid this process including formal structured history tools such as the Autism Diagnostic Interview (ADI-R) and the Diagnostic Interview for Social Communication Disorders (DISCO), and observational tools such as the Autism Diagnostic Observation Schedule (ADOS) and the NEuroPSYchological developmental assessment (NEPSY).

This is a lengthy process, our own study of practice in UK based Child Development Centres suggests this takes around 13 hours of professional time to complete, costing around UK £800 (US \$1200) per child (Galliver et al., in submission). This figure does not include costs of ongoing care or further investigation, for example to look for an underlying genetic or chromosomal disorder, nor co-morbid conditions such as ADHD and Developmental Coordination Disorder, even though associated costs may be well in excess of £2.7 billion per year (Knapp et al, 2009). Galliver et al, (in submission) also identified that most teams (10/12) employ a 2 stage process with an initial 60-90 minute screening, or general developmental clinic, often carried out by a paediatrician working alone, at which a decision is made as to whether there is sufficient evidence to justify proceeding to the full multidisciplinary diagnostic assessment (NICE, 2011). With a steady increase in referrals, diagnostic services are coming under increasing pressure to meet the level of need, frequently resulting in waiting times to complete assessment in UK of between 6 months and 2 years (Autism Achieve Alliance, 2014). Therefore any approach that can ease pressure on diagnostic pathways, for example by improving decision making at initial contact, has the potential to improve the quality and speed of the patient journey through the system and even to reduce costs.

2. THE PIRATE APP

2.1 Background

The initial inspiration behind the Pirate Adventure Autism Assessment App (Pirates) concept was a toy pirate ship in the child development clinic. The toy pirates were used in developmental play assessment of the child using a story line based on the Sally Anne Test (Baron-Cohen et al., 1985), a well-established test exploring the child's ability to know what someone else is thinking (Theory of Mind or ToM), thought to still be central to Autistic thinking following the longitudinal SIBS studies (Chawarska et al., 2014). In the original Sally Anne Test, two dolls, Sally and Anne, hide a toy. Anne then goes away, and whilst she is away, Sally hides the toy somewhere else. When Anne returns the child is asked where Anne will look for the toy. A child with typical theory of mind should be able to realise that Anne does not know the toy was moved and therefore will look where she helped Sally to hide the toy originally. We replaced Sally and Anne with two pirates, and the toy with treasure, which appeared to engage the child's interest, the majority of whom are boys, and contributed to the picture of the child. Sometimes unexpected extra information emerged, for example one child objected to the use of a single coin to represent the treasure, demonstrating a pedantic response typical of a child with Asperger's syndrome. Another child demonstrated a higher order of theory of mind, helping to exclude an ASD diagnosis, commenting that whilst the returning pirate would expect the treasure to be where he helped to hide it originally, he might look elsewhere if he thought the other pirate was untrustworthy. Around the same time we discovered Lego Mini-figures, including a range of pirates. These are produced with a wide range of facial expressions, offering the possibility of creating scenarios matching tests of recognition of facial expression (affect recognition), another common area of weakness in children with ASD. With this in mind we conducted a detailed review of the literature underpinning psychometric assessment of children with possible ASD, and around how to design ASD friendly apps.

2.2 Literature Review

A literature search was conducted using the PsycINFO database using the search terms "autism AND (screening OR diagnostic)" to explore available diagnostic and screening tools, yielding 39 relevant studies. A similar search was conducted on current clinical trials databases, and exploring the "app store" for autism diagnostic tools. Current clinical practice and the role of diagnostic tools such as the ADOS and NEPSY were also observed. The review also covered the original literature of psychological theories underpinning current testing including Theory of Mind, False Belief Tests, Affect Recognition and Francesca Happe's "Strange Stories".

Storyboards which have subsequently been built into the tool were constructed incorporating the identified tests, adapted into the context of a pirate adventure story line. This included tests of:

- Affect recognition (e.g. see Golan et al., 2010), including ability to match facial expressions (see Figure 1), identify appropriate situational facial expression (e.g. "how does the captain feel about being made to walk the plank?"), and short-term recall of facial expression.
- First Order Theory of Mind, adapting the "unexpected contents (Smarties tube) task" (Figure 2) and Sally Ann tests.
- Second Order Theory of Mind (Perner and Wimmer, 1985).
- Strange Stories exploring the child's ability to recognise and explain the use of sarcasm and a lie (Happé, 1994).
- Understanding of Idiom, such as "the treasure cost him an arm and a leg" (Barton, 2012).

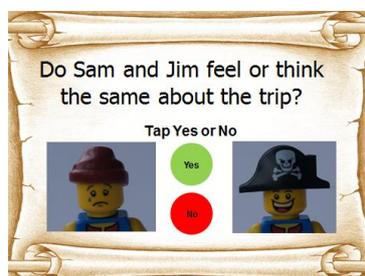


Figure 1. Example of affect recognition slide

A further search explored the principles of app design for children on the autistic spectrum. Design features likely to improve engagement included:

- Text should be concise, literal and unambiguous, readable and avoiding capitalising whole sentences.

- Navigation should be clear, e.g. using tap or swipe with clear prompts e.g. buttons or arrows. Buttons should be large and finger friendly.
- Design features should include: uncluttered layout, engaging format and story line, clear feedback (e.g. progress bar), visual images, simple colour palette avoiding black text on white background (visually over stimulating), using easily readable font such as Sans Serif, no time restrictions and no penalising (“errorless learning”), avoiding flashing, fast animations (avoiding sensory overload), abrupt changes, whilst using prompting and reinforcement (Fletcher-Watson, 2015).

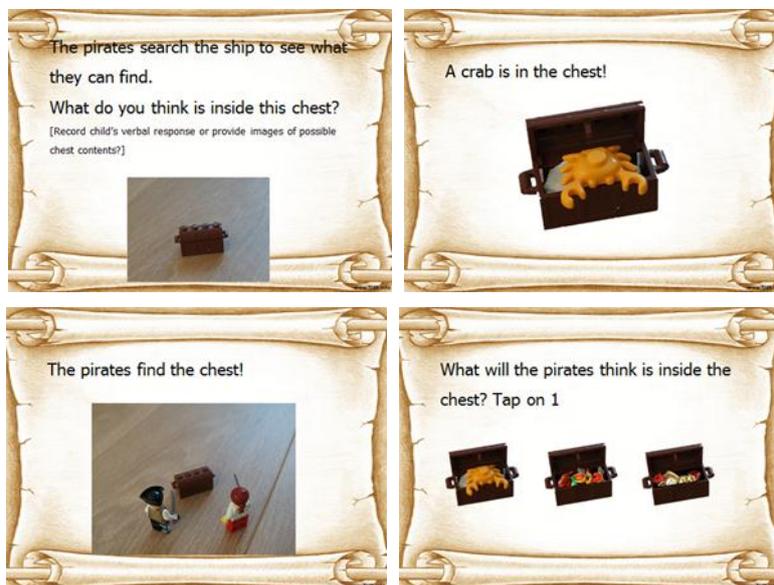


Figure 2. *First Order Theory of Mind Test adapted from Unexpected Contents False Belief Task.*

The resulting scenarios were built into a sequential pirate adventure story line, although most of these can be used as stand-alone tests. The initial PowerPoint and subsequent Apple IOS/Windows versions have incorporated the recommended design features, for example having a Flesh-Reading Ease score of 93.7 (0 unreadable, 100 most readable), use of ellipses, as often used in comics, between slides to maintain suspense, use of a progress bar and touch/tap buttons and Sans Serif.

3. EARLY CLINICAL EXPERIENCE

The app has been piloted by paediatric consultants working in 3 local Child Development Centres, 2 at initial appointment, in 1 at a diagnostic clinic. Results, including correct/incorrect responses, and the child’s interaction with the tool and clinician, are currently recorded in paper format whilst adherence to medical device regulation and data protection is completed. Feedback from the consultants and parents has been positive:

- It helps in creating a picture of the child. Whilst this includes results from the individual tests, additional information has emerged including how the child interacts with the clinician, such as when one child commented as the clinician expressed surprise at there being a crab in the treasure chest “are you afraid of crabs?”, misinterpreting the clinician’s emotions and facial expression. This mirrors observational information obtained in a full diagnostic assessment using tools such as ADOS and NEPSY, which can take 1-2 hours to complete.
- When used in combination with parental history and information from the child’s educational setting this can help in deciding whether the child needs to proceed to full diagnostic assessment, or even in reaching a diagnostic conclusion.
- Parents like the fact that the doctor has been seen to “do a test for autism” and engage in seeing their child’s ability either to perform the tests correctly (which can help in reassuring the parents) or to struggle, suggesting further assessment is required.
- Most children engaged with the familiarity of the Lego Mini-figures, the opportunity to play on a computer/iPad, and with the pirate theme.
- One consultant commented it was helpful having an observational tool to use with school aged children, mirroring use of observation of early development and play used in clinic with pre-school children.

- The app takes on average 10 minutes to complete, fitting into a standard 60-90 minute clinical appointment.

4. DISCUSSION AND CONCLUSION

Whilst this short paper reports very early results, it is encouraging that clinicians experienced in assessing children with possible ASD, have reported very positive experiences around use. The tool appears to provide information about the child's patterns of thinking; equivalent to psychometric testing used in full diagnostic assessment, and when used together with parental history and school questionnaire can help give a more complete picture of the child when deciding whether to proceed to diagnostic assessment. Parent feedback has also been very encouraging, one parent even asking if she could purchase the app to help teach her child to recognise different facial expressions. Initial impressions suggest a good correlation between performance on the tool and the presence of symptoms of possible ASD from parental history and school questionnaire. Further studies are needed to assess the performance of typically developing children, and whether this alters with age. This needs to be compared with performance in children with known ASD, and other conditions such as language disorder and learning difficulties that present with symptoms similar to children on the autistic spectrum. It will be important to ascertain, for example, whether there are different performance patterns in the different diagnostic groups, such as specific weaknesses in language based tests in children with language disorder. This early experience, along with discussion with experts in psychological testing for children, has highlighted a couple of areas that would benefit from adaptation, for example:

- Modifying the storyline used to test the child's level of understanding of tasks for second order theory of mind.
- Use of a clinical observational checklist.
- Potential incorporation of videoing child-clinician interaction.
- Recording reaction times on certain screens to help discriminate ADHD/ASD.

Early experience suggests that the tablet-based tool could become a useful adjunct to initial assessment of children referred with possible ASD.

5. REFERENCES

- Autism Achieve Alliance. (2014) Autism Spectrum Disorders: Waiting for assessment. Executive Summary. Autism Achieve Alliance.
- Baron-Cohen S, Leslie AM & Frith U. (1985) Does the autistic child have a "theory of mind"? *Cognition* **21**, pp. 37-46.
- Barton M. (2012) *It's raining cats and dogs: an autism guide to the confusing world of idioms, metaphors and everyday expressions*, London: Jessica Kingsley.
- CDC. (2014) Prevalance of autism spectrum disorder among children aged 8 years, Autism and Developmental Monitoring Network, 11 sites, United States, 2012 *MMWR Surveill Summ*, pp. 1-23.
- Chawarska K, Shic F, Macari S, Campbell D, Brian J, Landa R, et al. (2014) 18-Month Predictors of Later Outcomes in Younger Siblings of Children With Autism Spectrum Disorder: A Baby Siblings Research Consortium Study. *J Am Acad Child Adolesc Psychiatry* **53**, 12, pp. 1317-1327e1311.
- Fletcher-Watson S. (2015) Evidence-based technology design and commercialisation: Recommendations derived from research in education and autism. *TechTrends* **59**, 1, pp. 84-88.
- Galliver M, Gowling E, Farr W, Gain A & Male I. (in submission) How much does it cost the UK National Health Service to assess a child with possible Autism? *Child Care Health Dev.*
- Golan O, Ashwin E, Y. G, McClintock S, Day K, Leggett V, et al. (2010) Enhancing emotion recognition in children with autism spectrum conditions: an intervention using animated vehicles with real emotional faces. *Autism* **40**, 3, pp. 269-279.
- Happé FGE. (1994) An advanced test of theory of mind: Understanding of story characters' thoughts and feelings by able autistic, mentally handicapped, and normal children and adults. *Autism* **24**, 2, pp. 129-154.
- Knapp M, Romeo R, Beecham J. (2009) Economic cost of autism in the UK. *Autism* **13**, 3, pp. 317-336.
- NICE. (2011) Autism diagnosis in children and young people: Recognition, referral and diagnosis in children and young people on the autism spectrum. NIHR (UK).
- Perner J & Wimmer H. (1985) 'John thinks that Mary thinks that . . .': Attribution of second order beliefs by 5- to 10-year-old children. *J Exp Child Psych* **39**, pp. 437-471.