



“ABOUT ME” – A Mobile app for autism

Parent, child and professional partnership to improve information sharing and support for children and young people with autism

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The challenges identified in diagnostic assessment of autism have been acknowledged at an international, national and regional level (NICE 2011, Autism Strategic Action Plan for Wales, 2008). Clinical experiences and evidence from research reflected the lack of clarity and transparency in the diagnostic process for autism and difficulties in information sharing and communication with families and professionals.

The “**ABOUT ME**” autism passport (paper version) was developed with advice and support from professionals involved in the diagnostic assessment process but most significantly it was led by parents and young people. It was developed to address the dissatisfaction of parents and professionals with the diagnostic process around autism. It clearly described and informed families about the diagnostic process and helped them in their journey through the assessment process. The passport enabled parents and children to access, “hold” and share information and thereby reduce stress and anxiety for families and children. It provided a low cost solution to well known information sharing issues and reduced stress and anxiety for families and children. It put the child at the centre of clinical practice.

A professional and parental partnership has driven this initiative from inception and this has already led to changes in work practice. The passport has been piloted in the autism clinics in ABUHB for over a year and outcomes suggest that this has further enhanced delivery of person centred health interventions and supported transparency and accountability in clinical practice. Feedback from professionals suggests that it enhances delivery of person centred care and supports transparency and accountability in clinical practice. The passport supports improved planning and management thereby reducing stress for everyone.

It was developed as a live interactive document which would continue evolving to meet needs of the children. Feedback from young people suggested the next stage of the passport should be available as a mobile app to keep abreast with technology and promote sustainability and be most acceptable to young people for whom such apps are their preferred means of communication and information management. The mobile app will allow access and share information with services easily especially at times of emergency e.g. a visit to A&E, when it is more likely to be available than a paper version. The mobile app will be easily accessible for updating information, less intrusive than a paper copy and easy to back up the information should the mobile phone or tablet break down or be lost. The investment in mobile apps will also make the passport sustainable without recurring costs for printing and memory sticks.

The team co-created specifications for the proposed mobile app with professionals, young people with autism and their families. The clinical team were successful in obtaining a

small grant from the Techealth innovation fund (Swansea University) last year which enabled us to start working with Peter Harvey (a young person with high functioning autism who has a passion for computers and mobile technology) and his father Dave Harvey (a radiologist by background but now a radiological IT developer and managing director of Medical Connections a small, medical software company). These credentials put Peter Harvey and Dave Harvey in an ideal position to lead the development of a prototype mobile app for ABOUT ME. Further collaboration with technology provider Sabarna Mukhopadhyay (SymlConnect Ltd) via the success at the Health Technology Challenge has enabled decisions on the most appropriate platform for development of the app with consideration of the design, layout and options for entry and back up of data.

Peter said: "At first when I was asked to do this project I was worried that I would not be able to complete it as early attempts to use Java and android ran into troubles, after weeks of trial and error I found that once you get into coding it is very easy to do some cool looking stuff (i.e. calling from within an app) and in some cases even easier than some of the more basic bits. This has greatly advanced my programming skills and I am now studying computing at Gower College Swansea, and I think this will help me for the future.

A younger version of me would have found this app great. This app is very streamlined so you can easily find what you're looking for, this was a fun experience".

The investment in mobile applications for tablets and smart phones will make the Autism Passport sustainable without recurring costs for printing. It will reduce time in duplicating history / information taking sessions. Having accurate information will mean that more suitable provision could be more easily identified and provided, which in turn will reduce anxiety and stress for the child/young person and family/carers and the number of high cost crisis situations experienced. The development of the mobile app will make **ABOUT ME** easily accessible to a much wider audience not only nationally but also across the world.

The principles of Co- production underlie the origins and development of the mobile app **ABOUT ME** and its usage will promote information sharing and better communication among professionals thereby reducing the need for duplicating assessments and interventions. It will enhance delivery of person centred health interventions and support transparency and accountability in clinical practice. Professional and parental collaboration has driven this initiative and has led to changes in work practice. The development of mobile app has proven to be a catalyst for further development as this framework could be used to work with children and adults with other lifelong conditions such as epilepsy, schizophrenia, or physical conditions such as diabetes and at times of transitions or crisis.