Storyboard submission

Follow the detailed instructions in this template for writing a description of your storyboard. Type your information in each section below and save this completed storyboard document as a Microsoft Word file.

Please spell check your storyboard before submission as it will be published on the NHS Wales Awards website.

Please note: The storyboard should be between 500 – 1000 words maximum (including references but excluding headings, images or graphs)

Submit your storyboard using the online submission system at www.nhswalesawards.org.uk by Friday 25 January 2013.

Storyboard submission

1. Storyboard Title

“About Me”- Autism Passport
A parent, child and professional partnership to improve communication and information sharing during diagnostic assessment of autism

2. Brief Outline of Context (Where this improvement work was done; what sort of unit/department; what staff/client groups were involved)

This passport was developed by professionals in the Child and Family Therapies Division, Aneurin Bevan Health Board (ABHB) with carers and service users from Gwent area in collaboration with the Welsh Government, as part of the Autism Spectrum Disorder (ASD) Strategic plan for South East Wales.

3. Brief Outline of Problem (Statement of problem; how they set
The “inspiration” for the passport came from the often quoted dissatisfaction of parents and professionals with the diagnostic process around autism. In September 2011 NICE made clear recommendations as to how families could be better informed and supported through the autism diagnostic process. Our clinical experiences and locally conducted research also reflected the lack of clarity and transparency in the diagnostic process for autism and difficulties in information sharing and communication with families and professionals.

4. Assessment of Problem and Analysis of its Causes
(Quantified problem; staff involvement; assessment of the cause of problem; solutions/changes needed to make improvements)

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, 2011).

During 2010-2011, professionals and services users were involved in a locally conducted qualitative research project on their views and experiences of the diagnostic processes used for the assessment of autism in children and young people in Gwent. The findings provided an accurate description of the diagnostic processes used in ABHB for assessing children with autism and insight into practitioners’ views on the diagnostic process. Most importantly this study highlighted the patients’ and families experiences of their journey through the diagnostic assessment. It identified good practice but also areas of difficulties. The common themes that emerged from the study were timeframe for assessment, poor communication and information sharing, parental frustration at having to repeat developmental histories and a lack of involvement in the process.

5. Strategy for Change (How the proposed change was implemented; clear client or staff group described; explain how they disseminated the results of the analysis and plans for change to the groups involved with/affected by the planned change; include a timetable for change)

“About Me”, the Autism Passport was developed with advice and support from professionals involved in the diagnostic assessment process but most significantly with advice and support from parents and young people. Families and children/young people with a diagnosis of autism were at the centre of this project and were involved from the outset in the development of the passport. The parent and carer consultation group provided input into the design, content and layout of this passport and the children/young people designed the logo for the passport. Particular attention was paid to details
such as the colours used for the passport, text, and layouts keeping in mind the sensory profile of children/young people with autism.

The aim of the passport was to clearly describe and inform families about the diagnostic process. It was envisaged that this would help them in their journey through the assessment process. A group of professionals from health, education, social services and the voluntary sector were also consulted at all stages during the development of this passport.

The input from children/young people suggested that the passport should be made available in a paper and electronic form (encrypted USB stick). Our goal was to make the passport accessible and to keep abreast with modern technology. The production of a digital story to complement the passport has made it easily accessible (https://vimeo.com/50496937 the password is: passport).

The passport was launched at a series of public events in autumn 2011 across Wales. It is available in English and Welsh, paper and electronic form. The pilot project in ABHB has started and passports are now being given to families and young people.

6. Measurement of Improvement (Details of how the effects of the planned changes were measured)

The philosophy of the passport is summarised by the following message from a parent

"Being told your child might have a disability can be a frightening and isolating feeling. This booklet outlines the process/procedure used during the diagnosis.

It also, vitally, gives you a named person to contact for those unexpected queries and worries. It also provides contact numbers, both nationally and locally. It is an 'interactive' booklet which involves everyone in the process. I would have found this really helpful when I was going through this process with my child".

An evaluation process has been established using qualitative methodology to gather information from families, young people and professionals. The consultation groups (both professional and parent) set up at the outset of the project will continue to provide feedback. The passport will support improved planning and management thereby reducing stress for everyone.

7. Effects of Changes (Statement of the effects of the change; how far these changes resolve the problem that triggered the work; how this improved patient/client care; the problems encountered with the process of changes or with the changes)

We are now working with other agencies across Wales and health professionals in ABHB to disseminate the use of the passport. Preliminary findings suggest the passport is a welcome initiative for parents and professionals. Holding a personal, easily accessible and accurate record addresses some of the frustrations reported by parents. Feedback from
professionals suggests that the passport enhances delivery of person centred health interventions. We are currently working on development of applications for tablets and smart phones.

8. Lessons Learnt (Statement of lessons learnt from the work; what would be done differently next time)

“About Me” has been a challenging but rewarding project as it has put the child at the centre of clinical practice. Professional and parental collaboration has driven this initiative and has led to changes in work practice. The passport is a live document and will continue to need development and modification as a child’s needs changes. This 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 and at times of transitions or crisis.

9. Message for Others (Statement of the main message they would like to convey to others, based on the experience described)

The Passport Project provides a low cost solution to well known information sharing issues and should reduce stress and anxiety for families and children.

Quote by a parent about the passport:
“I do think that a passport is useful as it focuses the mind on what is positive. There was so much negativity at the point of my son’s diagnosis that I would have welcomed any approach that viewed my son as a child rather than a problem.”