



Improving Services for Children with Autistic Spectrum Disorder and their Families

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Introduction

Autistic Spectrum Disorder (ASD) is a lifelong developmental disability affecting 1 in 100 people and resulting in varying degrees of difficulty with social communication, social interaction and social imagination.

Within Royal Manchester Children's Hospital (RMCH) it was observed that this patient group were often stressed, agitated and distressed by unfamiliar hospital surroundings and interventions.

A multi-disciplinary and interagency group formed aiming to improve the experience of these children.

Two consultation events were held to explore users' experiences and perceptions of current and best health care practice.



Figure 1. Conference

Outcomes

- Training/Awareness
- Improved communication tools
- Individual care pathways
- Positive patient experience

Jack's story

Jack is a 17 year old young man with ASD, epilepsy and learning difficulties. He presents with challenging behaviours due to sensory differences and anxiety when he experiences stress. Currently Jack attends a residential school.

Jack has a history of being unable to access healthcare services. He has been unable to receive the interventions that he needs at a number of hospitals including RMCH.

References

- Human Rights Act 1998
- UNICEF Convention on the Rights of the Child 1989
- National Service Framework for Children 2003
- Every Child Matters Aiming High for Disabled Children 2004
- Safeguarding Children's Act 2004
- Disability Discrimination Act 2005
- Better Services for people with an ASD 2006
- Autism Act 2009
- NICE guidance 2010 (in progress)

Acknowledgments

We thank the children and young people with ASD and their carers for working with us to enhance quality of care

For further information

- <http://www.nas.org.uk>
- www.positiveaboutautism.co.uk
- <http://www.nes.scot.nhs.uk/asd/references/index.htm>

Identified risks using a standard care pathway

Using the risk management process the following potential risks were identified:

Risks to patient

- Delay in receiving medical intervention
- Potential negative effect on patient's health
- Challenging behaviour puts patient at risk
- Negative experiences makes future hospital engagement difficult between patient and hospital and impacts future admissions/appointments

Risks to carers

- Patient's challenging behaviour puts the carers and others at risk

Risks to organisation

- Patient's challenging behaviour puts healthcare professionals and others at risk
- Financial costs and increased waiting time to RMCH due to ineffective use of resources

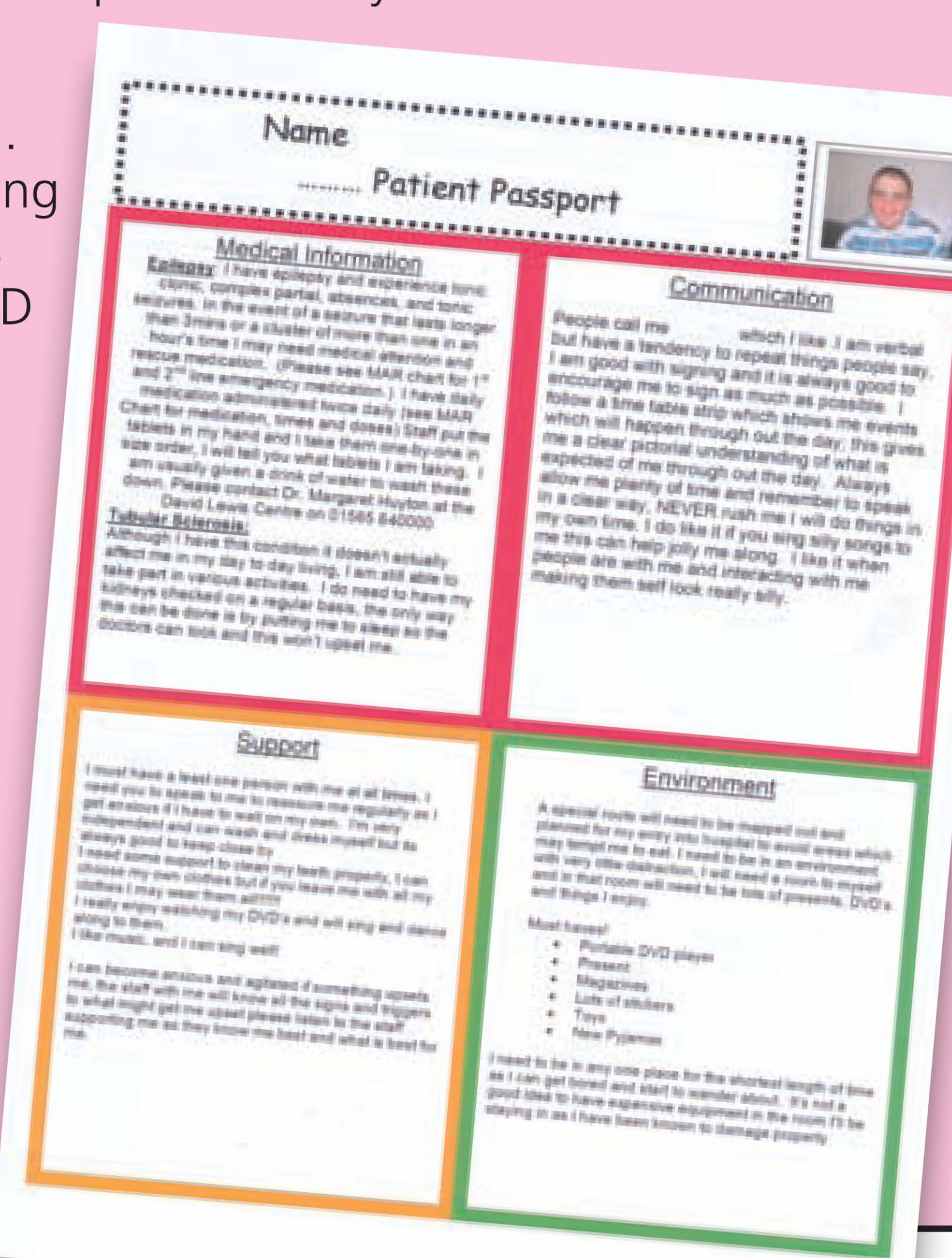
Conclusion

Risk – medium – to patient and organisation

Action plan

- Reduces risk of patient cancellation
- Reduces risk of stress to patient, family and staff
- Ensures more effective use of Trust resources
- Improves patient safety

Figure 2. Identifying patients with ASD



Minimising risks by individualising Jack's care pathway

It was identified by the Pre-admission Nurse that Jack needed a different pathway to prepare him for Magnetic Resonance Imaging and Echo scans under general anaesthetic.

1. Assessment of Jack's individual needs

- Prior to hospital admission was assessed at home using a tailored assessment tool.
- A planning meeting was held with parents and carers.
- A risk assessment was carried out.

2. Methods of communication

- Photographs of key areas and equipment in the hospital were used to help communicate to Jack what would happen during his hospital admission.
- Jack had an individualised visual timetable to help him make sense of the sequence of events that would occur.
- Jack needed extra time to process the information.
- Patient journey documented and communication passport circulated to the multi-disciplinary team.

3. Patient safety

- Initial assessment took place in Jack's home instead of the hospital setting.
- Key workers:
 - Had been trained to use safe holding techniques.
 - Accompanied Jack to the hospital.
 - Carried out simple interventions under health professionals' instructions such as
 - Took Jack's weight and height at home instead of at hospital.

4. Environmental Issues

- Be admitted to hospital by a different entrance and exit as he was unable to cope with:
 - Passing the hospital shop.
 - Areas where there was sight or smell of food.
 - Seeing other children.

5. Changes to clinical practice

- Jack's waiting time in hospital was reduced as he was admitted directly to Radiology instead of the ward.
- Jack's need for personal space respected by using a quiet, uncrowded and uncluttered waiting area.
- Hospital identity band attached to Jack's medical case notes instead of his wrist.
- Cannula removed in theatre instead of on the ward.
- Cubicle and named nurse identified on the ward for recovery time.
- Went home early with permission of the Anaesthetist and agreed plan of care.

Conclusions

- Jack was able to access the healthcare that he needed and the experience was more positive for him, his carers and healthcare professionals.
- Reasonable adjustments can be made by healthcare staff to help children and young people with ASD cope better with hospital appointments and admissions.
- Working in collaboration with parents and carers of children and young people with ASD ensures the best approach.
- Awareness of ASD training sessions for staff is important to promote understanding of the condition and the patient's individual needs.

Figure 3. Staff education poster

