

## Continuous Service Quality Improvement and Change Management for Children and Young People with Autism and Their Families: A Model for Change

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### ABSTRACT

A case study approach was used that included data collection from a wide range of sources, e.g., a stakeholder conference, audit, questionnaires, and evaluative feedback from carers, families, staff, and Autism Champions. Integrated pathways for patient care improvement were developed. Families and carers were involved in raising awareness of the needs of children with autism and policy development to meet these needs. Increased involvement from interdisciplinary working strengthened the work of the Recognising Autism Management Programme (RAMP) and improved patient care outcomes. The interventions undertaken by the RAMP resulted in improved patient /carer satisfaction, the reduction of challenging behaviour, complaints, and treatment refusal. The Autism Champions played a significant role in signposting resources and the cascading of education and practice development. All children and young people (0–25 years) on the Autism Spectrum and their families benefit from safe, individualised, high quality care in a supportive environment. Education of staff and families and targeted actions in adapting attitudes and behaviours in communication and care management will result in positive experiences for staff, children and families and financial benefit to the NHS Trust by reducing cancellation of appointments and operating theatre slots.

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## Introduction

Autism is a spectrum of developmental disorders characterised by deficits in verbal and emotional communication, social reciprocal interaction with stereotyped, repetitive, or unusual behaviours or interests (Inglese, 2009; Levy, Mandell, & Shultz, 2009; Rabin, 2002). Autism is referred to as a spectrum of disorders because its manifestations can occur in a variety of combinations and be present in varying degrees of severity (Inglese, 2009). Although the term autism will be used in this article, it also refers to children and young people with Asperger's

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syndrome, pervasive developmental disorder, and learning disabilities as there appears to be a strong correlation between learning disability and co-morbidly occurring as autism. Although there is a dearth of specific data, it appears that children with learning disabilities may also have a reduced ability to understand new and complex information (DH, 2009; Howlin, 1998). This inability to comprehend complex information is related to limited language skills, which reduce the child's ability to report their symptoms or distress, which may be manifested as challenging behaviours (MENCAP, 2004).

Autism is an increasingly recognised condition and it is suggested that 1–2% of the primary school aged population in the United Kingdom may be affected (Baron-Cohen, Scott, Matthews, & Brayne, 2009). In 2014 within the Greater Manchester health district, it was estimated that approximately 89% of all children referred to child and adolescent mental health services (CAMHS) had a diagnosis of autism (unpublished data). It is recognised within the United Kingdom that Greater Manchester as a conurbation has the largest population of children with a diagnosis of autism.

For Royal Manchester Children's Hospital (RMCH), a tertiary provider of paediatric health care in the north west of England this therefore has a large impact upon service provision. Approximately 82% of children and young people with autism have co-existing disorders such as language disorders or attention deficit hyperactive disorder (ADHD), which also affect their behaviour (Levy et al., 2009). In addition, children and young people with autism often have coexisting health care needs such as seizures, gastrointestinal problems, allergies, and sometimes intellectual disabilities, which require continued management and access to a comprehensive range of healthcare services (Liptak, Stuart, & Auigner 2006). This poses difficulties for health care providers as the child's behavioural responses to medical investigations and interventions are frequently not predictable (Scarpinato et al., 2010; Volkmar, Weisner, & Westphal, 2006).

Children with autism often find the experience of attending a medical setting frightening because of their inability to cope with change and comprehend what is happening to and around them (Bultas, 2012; Jones, 2006; Vaz, 2010). Sensory overload from lighting, noise, crowded and busy areas, as well as unpredictability of waiting times may result in overwhelming anxiety, withdrawal, or negative behavioural outbursts (Sanz-Cervera et al., 2015; Vaz, 2010).

The Department of Health (DH) (2015) clearly sets out the expectations of all healthcare professionals and services in meeting the individual needs of children and young people with Autism as stipulated within the Monitor Framework (DH, 2015a) and Autism Act, 2009.

## Context

Within RMCH a group of multi-professional healthcare practitioners (children and young peoples' nurses, doctors, radiographers, physiotherapists, and specialist

play staff) became aware of the unmet needs of patients with autism who, when receiving hospital care, presented with challenging behaviour. The healthcare staff realised through their shared clinical experiences that patients with autism had individual communication, behavioural and sensory needs ([Appendix](#)) Some children and young people became stressed, agitated, or distressed because of their difficulty in understanding changes to their routine or when faced with unfamiliar or busy surroundings. Others could not tolerate being touched or having to participate in any activity that was new to them; such as radiological investigation procedures, general anaesthesia being administered for procedures/surgery, or when undergoing blood tests or complex wound care (Kennedy & Binns [2014](#); Khan, [2007](#)).

Particularly challenging environments for this group of patients were the Accident & Emergency and Outpatient departments. This is supported by the work of Vaz ([2010](#)) who argued that the lack of time to prepare for emergency hospital treatment was a significant factor (Pratt et al., [2011](#)). Discussions by interested parties in response to parent/carer feedback concluded that the care provided for children and young people with autism who attended RMCH could be significantly improved as in some cases children did not receive the healthcare needed.

On reflection, it was evident that many healthcare professionals involved in delivering care to children and young people with autism did not fully understand the disorder or the impact of the condition on patients and their families accessing hospital services (Kennedy & Binns, [2014](#)).

## National Guidance on Inclusiveness

The DH recognises that people with autism find it harder than others to make sense of everyday situations; whilst acknowledging that organisations should be inclusive (DH, [2006](#), [2009](#), [2010](#), [2014a](#) [2015a](#); NICE Guidance CG170, [2013](#)). DH ([2015b](#)) indicates that organisations must, therefore, make reasonable adjustments to lights, sounds and smells; as well as physical design to ensure that services are accessible to each individual patient. In order to make meaningful, positive adjustments to the care milieu and improve the experience of children with autism and their families it is recognised that staff would need education and training (DH, [2015a](#))

A diverse range of legislation states that children and young people with neurodiversity such as autism need to be given the same opportunities as neurotypical children without autism, and where possible to understand and support them in making choices about their health care (Autism Act, [2009](#); Children and Families Act, [2014](#); DH, [2006](#), [2008](#), [2009](#), [2010](#), [2014a](#) [2015a](#); NICE Guidance CG170, [2013](#); NICE Guidance NG11, [2015](#); NHS Confederation, [2009](#)). Organisations that hold responsibility for children's services need to therefore understand the particular needs of children and young people with a vulnerability

due to their specific individual needs and requirements and provide targeted communication and training resources.

## Method

### *Parent Engagement, Shared Decision Making and Identification of Client Group*

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In order to support anecdotal evidence and to improve the care pathway for children and young people with Autism, information was gleaned from several RMCH stakeholder events (Figure 1) which revealed that most parents of children and young people with autism felt stressed before they

**Improving Services for Children with Autistic Spectrum Disorder and their families**  
**Tuesday, 8th September 2009**  
**9.30 am – 3.30 pm**  
**Salford University**

**Aims of the event:**

This will be an interactive forum to consult on current and best practice for children and young people with autistic spectrum disorder by:

- Listening to parents/carers views of the current service
- Exploring and sharing experiences of children and their families with autistic spectrum disorder within healthcare services
- To establish a joint view on an appropriate healthcare pathway

**Who should attend?**

- Parents and carers, and young people with autistic spectrum disorder
- Acute and community services
- Allied health professionals and play specialists
- Anaesthetists, paediatricians, surgeons and general practitioners
- Child and adolescent mental health professionals
- Educational professionals and teachers
- Healthcare professionals
- Paediatric nurses

**The event is free to parents and carers**

The price for professional staff is £35

To register your interest please e-mail:  
[chris.hopley@cmft.nhs.uk](mailto:chris.hopley@cmft.nhs.uk)  
 or telephone  
 0161 701 5100

Central Manchester University Hospitals NHS Foundation Trust  
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 A Greater Manchester University

08/09/2009 09:46

Figure 1. Consultation with families, carers and healthcare providers & service evaluation.

even arrived at the hospital as they anticipated challenges with staff, hospital processes, and their child's behaviour (Gordon 2012). This reportedly stressful experience had a negative impact on the whole family and the staff involved in delivering patient care (Gray 1993, 2002). Perceived barriers to satisfactory hospital experiences included environmental factors such as poor car park facilities or busy waiting areas. These often resulted in failed medical interventions, such as cancellation of operating theatre slots, out-patient appointments, or investigations as well as radiology appointments not proceeding as planned. A multidisciplinary RAMP Steering Group including representation from the local National Autistic Society, the children's hospital, parent carer representatives, and a higher education institute was formed with the aim of raising awareness and redesigning the hospital care provision for children and young people with autism. In response to local need and national guidance, RAMP's vision was to ensure that the specific requirements of children and young people with autism were met on each visit to the RMCH. A 5-year comprehensive work plan was developed which included autism training for different specialty teams across RMCH.

As patients with autism have both general and specific health care needs it was recognised that an important first step was to identify this group of patients more consistently for both planned and unplanned admissions that meet the expectations indicated by the Department of Health (2015) framework.

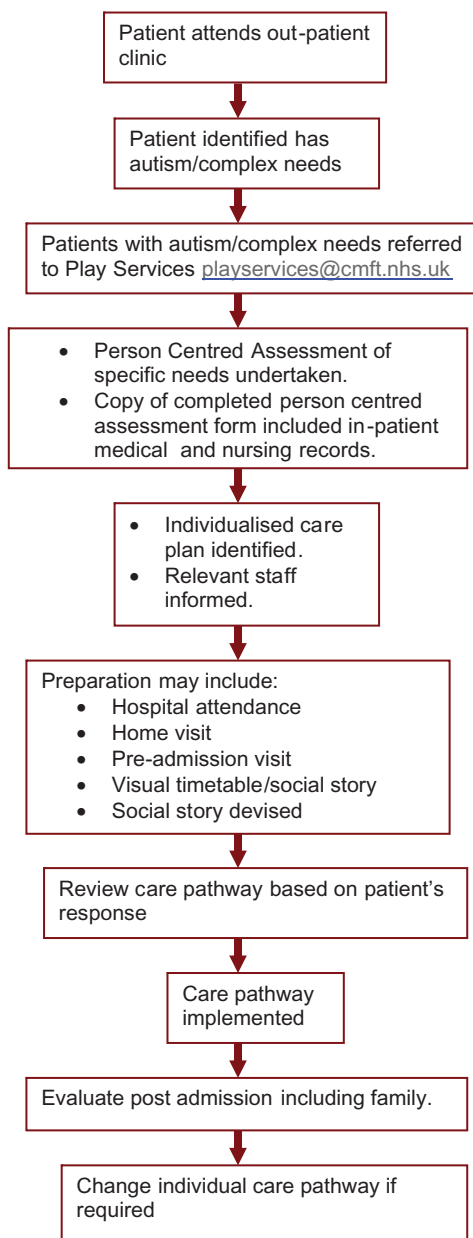
Pilot areas were initially identified through auditing current practice including the Elective Treatment Centre and Radiology departments. Through staff education, training to raise awareness, and the changing of expected processes, children and young people with autism began to be identified at pre-admission clinics. Parents and carers of children with autism reported that advance preparation and information sharing are key factors to their child having successful planned medical appointments (Figure 2).

Staff also observed that some children and young people coped much better if familiar staff and parents dealt with them for subsequent hospital visits. Quiet zones and the utilisation of "patient pagers" were instituted for children and families unable to wait or cope with crowds or noisy environments. Other patients benefitted from having a minimum waiting time agreed or by entering the hospital through a different entrance. Families were offered an opportunity to visit the hospital prior to their procedure to familiarise them and were provided easily read information about the environment, equipment, and staff through a range of communication methods (Figure 3 and Figure 4).

Prior to attending for treatment, other young people with autism found a pictorial view of their hospital journey using photographs and social stories useful (Gray 1993, 2002). Hospital staff worked in collaboration with parents, schools, and community healthcare staff to gather information about patients' specific needs in advance of hospital procedures and working in partnership to deliver safe and individualised care (Autism Act, 2009; Children and Families Act, 2014; DH,



## ELECTIVE ADMISSION PATHWAY FOR CHILDREN and YOUNG PEOPLE with AUTISM and Learning Disabilities

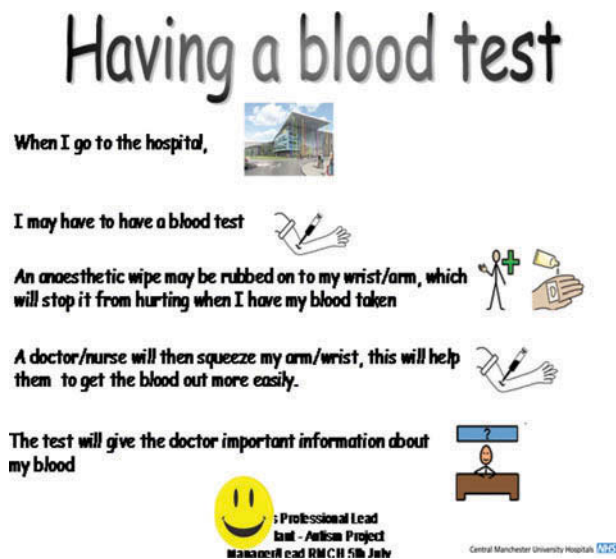


**Figure 2.** Pathways developed to meet the specific needs of group of children and young people with Autism.





**Figure 3.** Communication tools to wards/departments.



**Figure 4.** Social story board to support communication and understanding

2006, 2008, 2009, 2010, 2015a; NICE Guidance CG170, 2013; NICE Guidance NG11, 2015; NHS Confederation, 2009).

Key elements of the redesign process are captured in Figures 1–7.

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### **Increasing Health Care Staff Awareness**

A regular training programme was developed to help raise awareness of the condition and help healthcare staff to deliver care to patients with autism more creatively. The bespoke teaching sessions delivered by Positive About Autism have been interactive, visual and fun (Positive About Autism, 2014).

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Through evaluative learning, staff have reported acquiring a better understanding of a variety of complex behaviours, often associated with patients and families with autism, and feel better equipped to use simple yet effective communication tools in their clinical practice.

For staff dealing with emergency situations, having a positive understanding of sensory issues and communication differences for patients with autism potentially makes a real difference to the patient's journey and quality of care delivered. For example, a young child with a diagnosis of autism being cared for in the paediatric critical care department may have an sensory processing disorder (Plowden, 2015), not being able to process or understand the myriad of different technological noises going on about them, i.e., ventilator and invasive monitoring alarms. The child responds by becoming combative and "difficult" to manage in the eyes of the unaware critical care practitioner, resulting in the child receiving unnecessary sedation. An aware practitioner may have offered ear defenders to the child to reduce the sensory overload and address the overstimulation caused as a result of the sensory processing disorder; the child therefore becoming calmer as their behaviour de-escalates and they become more easily cared for.

To date several hundred hospital staff have participated in bespoke training including representatives from audiology, counselling, patient complaints, dietetics, occupational therapy, orthotics, physiotherapy, play service, psychology, radiology, and reception. Including reception staff is particularly important as often receptionists are the first point of contact for patients with autism and their families; for example arranging appointments and answering queries. Different ways of working in clinical areas continue to evolve as staff become more confident using different communication techniques and become familiar with making reasonable adjustments to their environment (Figure 5). These measures help optimise clinical outcomes for children, young people, and adults with autism to improve their hospital experience. Industry and business are following a similar model in order to ensure they are truly "Autism Friendly" as determined by statutory requirements enshrined in law (Autism Act 2009, DH, 2014b).

Awareness was also raised by inviting parents and carers of children with autism to share their experiences and reflect upon the impact of living with autism and accessing healthcare services. This included presentations on the medical Grand Round and Autism Champion training as well as evaluations of proposed clinical documentation including care plans and policy development. To support the process of training Autism Champions throughout different specialities across the organisation, "Ten Top Tips" for professionals, parents, and carers were requested and developed in partnership with the Greater Manchester Autism Consortium (GMAC, 2014) to support the process of embedding knowledge of autism into practice.



### Improving the Experience of People with Autism Spectrum Disorder in Health Care Settings

Communication Dos and Don'ts for People with Autism Spectrum Disorders	
DO's	DON'TS
Minimise waiting time and facilitate progression through admission etc quickly. If waiting is unavoidable, find a quiet secluded waiting area.	Make the person with an Autism Spectrum Disorder endure prolonged waiting time unless there is no alternative
Explain why and how you need to touch him/her. Use pictures, diagrams and written information to complement verbal	Initiate physical contact without first warning them or explaining what you plan to do
Get all the information you can from the carer who know best the person's needs and the best approach	Make assumptions about the person or the carers' needs, ask for information or clarification
Be aware that expressive language may not match age or behaviour	Forget that it may be frightening if the person either doesn't understand or takes things literally
Try to locate the bed in a quiet part of the ward and inform all staff of this need.	Expect the person and family to cope with a noisy environment e.g. from equipment, phones ringing etc.
Discuss the young person's medical history and diagnosis in plain language that s/he can understand even if they do not appear to be listening.	Assume that because a young person doesn't speak he/she doesn't understand what is being said. The person may understand fully but may not give any indication of this.
Recognise that the person may not make eye contact, may ignore verbal communication and may exhibit unusual behaviours.	Ignore the person or exclude them from conversations with their carer(s)
Recognise that repetitive behaviours may be used to reduce anxiety and distress particularly in unfamiliar environments.	Allow behaviours such as flapping, spinning, or ignoring staff to inhibit communication
Ascertain specific food preferences and if choices are not available ask the family to supply the desired food	Expect the person to eat food that may be different in presentation, kind, colour, shape or texture.
Give clear unambiguous explanations with realistic timescales and support with written information where possible. Predictability = stability!	Spring surprises, adaptation to change is very difficult for persons with Autism Spectrum Disorder.

#### Bibliography

- Baron-Cohen, S. ; Scott, F. J.; Matthews, C. F. E. and Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry*, 194: 500-509.
- Brooks, R.; Marshall, M.; Fraser, W. (2004) Autism spectrum disorder: how to help children and families. *Current Paediatrics* 14 pp 208-213
- Chamman, T.; Stone, W. (2006) Social and communication Development in Autism Spectrum Disorders. The Guildford Press.
- Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders published: *SIGN* guideline 96, June 2007; National Autistic Society (2009) Adult Autism Strategy [www.nationalautisticsociety.org.uk](http://www.nationalautisticsociety.org.uk)
- Department of Health (2004) National Service Framework for Children, Young People's and Maternity Services
- Johnson, N., Bekhet, A., et al. (2013). Attributed meanings and strategies to prevent challenging behaviours of hospitalised children. *Journal of Pediatric Health Care* (in press) 1-4
- NICE (2011) <http://guidance.nice.org.uk/CG157/6/consultations/1>
- Scarpinato, N., Bradley, J., Kurtz, K., Bateman, X., Holtzer, B., Ely, B. (2010). Caring for the child with an autism spectrum disorder in the acute setting. *Journal for Specialists in Pediatric Nursing*, 15(3): 244-254.
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**Figure 5.** Educating staff about Autism: "Communication Do's and Don'ts".

### Undergraduate Education About Autism

Locally the RAMP has had a positive influence on undergraduate health professional education programmes by raising awareness of the impact of autism. Examples of collaborations included taught lectures and experiential learning for a range of multi-professional students who undertook their role-emerging placement at RMCH looking at the individual needs of patients with autism in an acute hospital setting. Case studies have been used as the vehicle for teaching

undergraduate student nurses about the manifestations of autism and appropriate communication strategies for children and young people who have these specific needs (Levy, 2009; Levy et al., 2010; May, 2005; Moton-Cooper, 2004). 230

All new staff within RMCH receive a robust induction programme that incorporates and facilitates the underpinning awareness of autism friendly working. Further pathways have been identified for development, e.g., a Transition Pathway. 235

### ***Supporting Transition to Adult Services***

Many of the comorbidities are chronic/lifelong conditions that warrant continued care into adulthood and transition into adult healthcare. Many families demonstrate anxiety when moving into the adult environment for continued care, with concerns raised about the competency of healthcare staff to care for their child (Department of Health, 2003, 2010; Hamdani, Jetha, & Norman, 2011; Singh et al., 2010). Literature suggests that transition should be holistic and a person centred approach (Colver et al., 2013), however, whilst specialist children's services are delivered via a dedicated children's hospital, the variety of specialist teams required when transitioning young adults with multiple healthcare needs are not necessarily available within this trust. This therefore potentially results in difficulties meeting their individualised needs to access appropriate healthcare. 240 245

It was evident when listening to service users that transition has not always been discussed, especially regarding future specific needs and reasonable adjustments. Brammer (2015) considers that parents of patients in their late teens have demonstrated concerns regarding transition, for example, the mother of a 16-year-old boy who hits her when he experiences something unpredictable being petrified when asked if the topic of transition had been discussed with her. The families of younger children had not considered transition as something they required. Despite the myriad of experiences that patients with autism and their families have had at RMCH, they have built relationships and confidence with the healthcare workers throughout their hospital journey support by the RMCH RAMP (Hamdani et al., 2011). Parents of children in their late teens expressed concern that the level of support for families with a child with autism would not continue when their care inevitably transferred to adult services (Hamdani et al., 2011). Brammer (2015) indicates that a working party within the Trust develop an action plan for young people with autism moving into adult care. 250 255 260

### ***Evaluation*** 265

Once a child or young person with autism was referred or identified, reasonable adjustments via a person-centred tool (Appendix) assessing

their unique patient journey was facilitated in partnership with parents /carers and the young person by the relevant healthcare professionals. To improve quality care provision a “Toolkit” consisting of a range of autism-friendly initiatives has been introduced. This includes a children’s hospital-wide Autism Care Standard, an Autism Training & Education Strategy, and development of the Autism Champion role.

With new ways of working established, significant improvements in care for patients with Autism were reported not only by parents, but also by staff from various wards and departments. Formal service user evaluations of personal experiences helped inform the future direction for the RAMP and as a result measurable hospital standards for patients with Autism have been ratified and agreed in line with statutory requirements (Autism Act 2009; NICE 2013, 2014; DH, 2014b).

Figure 6 and 7 capture perspectives of carers who experienced reduced stress levels on bringing their child to hospital and accessed hospital treatments safely and successfully.

### Next Steps

The goal is now to ensure this level of care to all children and young people with autism at RMCH is maintained especially during transfer of their care to adult services. Hospital care standards for patients with autism have been ratified; thus providing an embedded audit tool and service user evaluation process. This process offers assurance for service users, commissioners and the organisation that quality of care for patients with autism continues to improve. Information leaflets for Clinical Care Commissioning Groups, education settings and acute

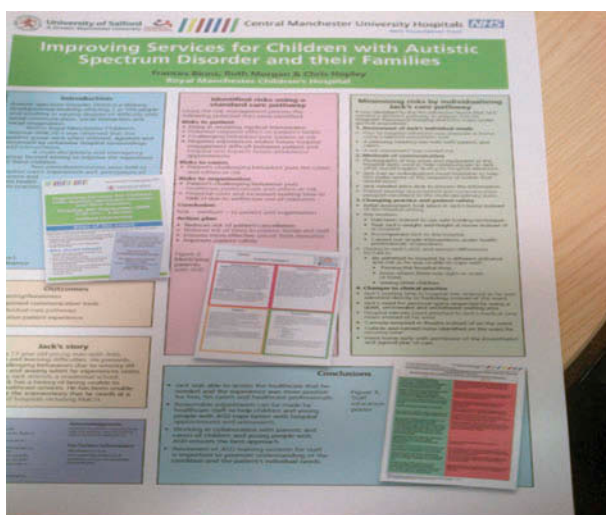


Figure 6. Parent /Carer Experience feedback.

“Your open and positive response was surprising in itself but your determination to improve the system was amazing ... those early meetings between the families of youngsters with autism and hospital staff from all disciplines were hugely productive and the zeal with which the raising of autism awareness was embraced by practitioners was breathtaking in its speed and depth.”

“When my child needed a number of teeth to be extracted, we were in dread. But as the process unfolded, we became more and more impressed. Every effort was made by the hospital to put the needs of the child first and for the experience to be as stress free as possible.”

“Provision was made so that we waited in a quiet area away from the hustle and bustle of a busy reception area. At all times my child was treated with kindness and respect.

There was recognition that his behavioural and sensory needs would benefit from him being in a room on his own, pre-op and post recovery, this was organised along with a DVD player and his favourite Lion King DVD.”

“Please keep up the good work, the prospect of adult services fills us with dread. It seems to me that your programme of awareness training is such that exposure to it by those working with adults who have autism would hugely benefit all.”

**Figure 7.** Service user feedback.

hospital environments exist to extend RMCH RAMP’s communication strategy as a mechanism to trigger the legal requirement for reasonable adjustments as early as permissible to improve access for patients and families with autism. A routine administrative alert (flag) is applied as part of the pathway process to facilitate inclusion at each stage of care delivery.

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**Conclusion**

Caring for children and young people with autism presents challenges for multi-professional teams. It is important that all professionals communicate effectively with each other and with the child and family, adjusting their behaviour and the environment so that the patient’s journey is dignified and tailored for their individual needs. Experience has highlighted that children with autism have protracted hospital stays and appear not to have all of their psycho-social needs met. Reflection on practice shows that lack of staff awareness is the key indicator and is associated with concerns related to patient/staff experience, rights, safety, and behaviour when providing care.

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Optimising the patient experience and that of their carers therefore supports the management and safety of everyone involved. One essential factor in the development of hospital care provision and improving practice is alerting health professionals well in advance that the individual has autism; preferably before the patient even comes to hospital. This allows staff to carry out a comprehensive assessment in collaboration with the child, their parents, and key members of staff. Parents being supported and encouraged to advise upon their child's care. Identifying any known triggers that cause a young person to present with challenging behaviours and how best to de-escalate or avoid a crisis is critical. Building a holistic picture of the child and agreeing on a pathway for their hospital journey helps meet the specific needs of the child or young person and maintain a safe, autism-friendly environment for everyone involved. The achievement of this necessitates a person-centred flexible approach to the adjustment of established pathways of care delivery; such as waiting times, environmental set up and recovery times which may need to be altered significantly to accommodate the patient's individual needs. Staff need to be aware that the benefits of taking such action far outweighs the drawbacks as the outcome may be less frequent incidents of refusal of treatment and reduced anxiety levels for the child and the family; which often leads to dissatisfaction. An in-house multi-professional e-learning package on Autism is to be developed to supplement the bespoke training; targeting a wider audience and raising levels of awareness in all professional groups.

The RMCH RAMP has shown to achieve high-quality, cost-effective patient care it is equally important that healthcare staff access training in autism. Healthcare professionals are therefore empowered and better able to work creatively with patients and families with autism to meet the legal requirements in making reasonable adjustments.

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## Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article. 345

## References

- Autism Act. (2009). (<http://www.legislation.gov.uk/ukpga/2009/15>).
- Baron-Cohen, S., Scott, F. J., Matthews, C. F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry*, 194, 500–509. 350
- Brammer, A. (2015). A service evaluation of the impact of person centred needs assessments for patients with Autism-Spectrum Disorder (ASD) prior to attending the radiology department. Bolton, UK: University of Bolton.
- Bultas, M. W. (2012). The health care experiences of the preschool child with autism. *Journal of Pediatric Nursing* 27, 460–479. 355
- Colver, A. F., Merrick, H., Deverill, M., Le Couteur, A., Parr, J., Pearce, M., ... McConachie, H. (2013). Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services. *BMC Public Health*, 13. <http://www.biomedcentral.com/1471-2458/13/675>. 360
- Department of Health. (2003). Transition: Getting it right for young people.
- Department of Health. (2006). Better services for people with an Autistic Spectrum Disorder.
- Department of Health. (2008). High quality healthcare for all.
- Department of Health. (2009). Valuing People Now: a new three-year strategy for people with learning disabilities. Making it happen for everyone. London, UK: Department of Health. 365
- Retrieved from [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_093375.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf)
- Department of Health. (2010). “Fulfilling and rewarding lives.” The strategy for adults with autism in England. London, UK: Department of Health.
- Department of Health. (2014a). The Children and Families Act. Retrieved from [http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga\\_20140006\\_en.pdf](http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga_20140006_en.pdf) 370
- Department of Health. (2014b). “Think Autism”: fulfilling and rewarding lives, the strategy for adults with autism in England. Department of Health 2014.
- Department of Health. (2015a). Statutory guidance for local authorities and NHS organisations to support implementation of the Adult Autism Strategy. London, UK: Department of Health 375
- Department of Health. (2015b). Monitor Risk Assessment Framework, Department of Health. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/455893/RAF\\_revised\\_25\\_August.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/455893/RAF_revised_25_August.pdf)
- GMAC. (2014). Greater Manchester Autism Consortium. Retrieved from <http://www.autismgm.org.uk/index.php> 380
- Gordon, A. (2012). The autism project: Children face up to four year wait for therapy. *The Star*.
- Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness*, 15, 102–120 385
- Gray, D. E. (2002). “Everybody just freezes. Everybody is just embarrassed”: Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*, 24, 734–749



- Hamdani, Y., Jetha, A., & Norman, C. (2011). Systems thinking perspectives applied to healthcare transition for youth with disabilities: A paradigm shift for practice, policy, and research. *Child: Care, Health & Development*, 37, 806–814. Available from: <http://web.b.ebscohost.com/>. 390
- Health and Social Care Act. (2012). c.7. London: The Stationery Office Limited.
- Howlin, P. (1998). Children with autism and Asperger Syndrome: A guide for practitioners and carers. Chichester, UK: John Wiley & Sons. 395
- Hudson, J. (2006). Prescription for success. Supporting children with autism spectrum disorders in medical environment. Lenexa, Kansas: Autism Asperger Publishing Company.
- Inglese, M. D. (2009). Caring for children with autism spectrum disorder part ii: Screening, diagnosis, and management. *Journal of Pediatric Nursing* 24, 49–59
- Johnson, N., Bekhet, A., Robinson, K., & Rodriguez, D. (2013). Attributed meanings and strategies to prevent challenging behaviours of hospitalised children with autism: Two perspectives. *Journal of Pediatric Health Care*, 28(5), 386–393. 400
- Jones, E. (2006). Going to the doctor: A guide for children with autistic spectrum disorder. London, UK: The National Autistic Society,
- Kennedy, R., & Binns, F. (2014). Communicating and managing children and young people with autism and extensive burn injury. *Wounds UK*, 10. 405
- Khan, J. J., (2007). A program to decrease the need for pediatric sedation for CT and MRI. *Applied Radiology*, 36, 30–33. Available from: <http://web.b.ebscohost.com/>.
- Levy, S. E., Giarelli, E., Lee, L. C., Shieve, L. A., Kirby, R. S. Cunniff, C., & Rice, C. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among multiple populations of the United States. *Journal of Developmental and Behavioural Pediatrics*, 4, 267–274. 410
- Levy, S. E., Mandell, D. S., & Shultz, R. T. (2009). Autism. *The Lancet*. 374, 1627–1638.
- Liptak, G. S., Stuart, T., & Aigner, P. (2006). Health care utilisation and expenditure for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders*. 36, 871–879. 415
- May, F. (2005). Understanding behaviour in people with autism and Asperger Syndrome. London, UK: The National Autistic Society.
- MENCAP. (1998). The NHS: Health for all? People with learning disability and healthcare.
- MENCAP. (2004). Treat me right! Better healthcare for people with learning disability. 420
- Morton-Cooper, A. (2004). *Health care and the autism spectrum*. London, UK: Jessica Kingsley Publishers.
- National Autistic Society. (2008). Social stories and comic strip conversations. National Autistic Society. Available at: <http://www.autism.org.uk/16261>.
- NHS National Patient Safety Agency. (2004). Understanding the patient safety issues for people with learning disabilities. 425
- NICE. (2013). Autism in under 19's: support and management. National Institute for Clinical Excellence Guideline CG170
- NICE. (2014). NICE Quality standard [QS51]. Retrieved from <https://www.nice.org.uk/guidance/qs51> 430
- NICE. (2015). Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. National Institute for Clinical Excellence, Guideline NG11
- NHS Confederation. (2009). Aiming high for disabled children: Every child matters.
- Plowden, L. (2015). Sensory processing in children with Autism Spectrum Disorder: Relationship with non-verbal IQ, autism severity and Attention Deficit/Hyperactivity Disorder symptomatology. 435

- Positive About Autism™. (2014). *Positive About Autism™*. Available at: <http://positiveaboutautism.co.uk/>
- Pratt, K., Baird, G., & Gringras, P. (2011). Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: a continuous quality improvement and change management programme. *Child: Care, Health and Development*, 38, 789–797. 440
- Rapin, I., (2002) Diagnostic dilemmas in developmental disabilities: Fuzzy margins at the edges of normality. An essay prompted by Thomas Sowell's new book: *The Einstein Syndrome*. *Journal of Autism and Developmental Disorders*, 32, 49–57. 445
- Sanz-Cervera, P., Pastor-Cerezuela, G., Fernández-Andrés, M-I., & Tárraga-Mínguez, R. (2015). Sensory processing in children with autism. *Research in Developmental Disabilities*, 45–46, 188–201.
- Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B., Ely, B. (2010). Caring for the child with an autism spectrum disorder in the acute setting. *Journal for Specialists in Pediatric Nursing*, 15, 244–254. 450
- Singh, S. P., Mioli, P., Ford, T., Kramer, T., Weaver, T., McLaren, S., ... White, S., (2010). Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. *The British Journal of Psychiatry*, 197, 305–312. Available from: <http://bjp.rcpsych.org/content/197/4/305.full-text.pdf+html> 455
- Vaz, I. (2010). Improving the management of children with learning disability and autism spectrum disorder when they attend the hospital. *Child: Care, Health, and Development*, 36, 753–755. doi: [10.1111/j.1365-2214.2010.01144x](https://doi.org/10.1111/j.1365-2214.2010.01144x)
- Volkmar, F. R., Weisner, L. A., & Westphal, A. (2006). Healthcare issues for children on the autism spectrum. *Current Opinion in Psychiatry*, 19, 361–366. 460

# Appendix Person-centred individual needs assessment.



Central Manchester University Hospitals **NHS**  
NHS Foundation Trust

Royal Manchester Children's Hospital

## **Reasonable Adjustments Required** **Person Centred Assessment of Child's Individual Specific Needs**

(To be placed on the front of Childs notes/care plan)

Patients Name ..... Hospital No..... Clinician.....  
 Patient with Autism ☐ Learning Disability ☐ Medical Complexity ☐  
 Communication Flag requested on ☐ PAS ☐ Bedman ☐ Other ☐  
 Reasonable Adjustments Completed: Yes ☐ No ☐ PCA Enclosed: Yes/No  
 Translator /Interpreter required Yes/No Requested Yes/No/ N/A  
 Date to be Admitted/Seen .....

Ward/Area .....

Actions Required.....

Room required due to individual sensory needs ☐

### **Important points to be Aware of on Admission or Appointment :**

#### **Red** **High Priority /Dislikes**

- 
- 
- 
- 

#### **Amber** **Medium priority**

- 
- 
- 
- 

#### **Green** **Likes/Interests**

- 
- 
- 

### **Assessment Completed Via:**

Telephone ☐ Ward/Department ☐ Other ☐  
 Parent ☐ School/Nursery/Senco ☐ Learning Disability Nurse ☐

Signed ..... Name .....

Professional Status ..... Date Completed .....



# Central Manchester University Hospitals

NHS Foundation Trust

## Royal Manchester Children's Hospital

### PERSON CENTRED ASSESSMENT FOR A CHILD/YOUNG PERSON WITH A DISABILITY

e g AUTISM/LEARNING DISABILITY

#### TO BE COMPLETED PRIOR TO ADMISSION/CLINIC

Patients Name ..... Hospital No..... Clinician.....  
 Patient with Autism ☐ Learning Disability ☐ Medical Complexity ☐  
 Communication Flag requested on ☐ PAS ☐ Bedman ☐ Other ☐

Name..... DOB.....

Referred by ..... Hospital No .....

Ward/Area..... Date..... Ethnicity.....

Contact No.....

Mental Capacity Assessment [ask if over 16 ] N/A ☐ Yes ☐ No ☐

#### History

1. Has your child been in hospital before? Yes ☐ No ☐

If yes, please state the experience

What was your child's experience of pain?

Communicate pain verbally? ☐

Don't know ☐

Points to the area of pain ☐

Unable to communicate pain ☐

Screams ☐

Hitting self ☐

Hitting others ☐

Other.....

#### Communication

2. What method of communication does your child/young person use?

Use Pictures ☐

Sign Language ☐

Verbal ☐

Auditory/ Hearing ☐

Use single words ☐

Other ☐

Sensory ☐

Interpreter /Translator required YES/NO

Does you or your child have a communication passport Yes ☐ No ☐

Would like photographs (social story ) forwarded Yes ☐ No ☐

Patient plan/journey to be devised Yes ☐ No ☐

#### Preparation to Hospital

3. Would your child/young person benefit from a pre-hospital visit to see the area?

Yes ☐

No ☐

NAME ..... HOSPITAL NO .....CLINICIAN.....

Comments.....  
.....

3. Is your child/young person able to give eye contact when communicating verbally?

Yes ☐ No ☐ Sometimes ☐

4. Are there any familiar sayings that you or your child/young person uses regularly which would be useful for the staff to know?

Yes ☐ No ☐ Sometimes ☐

If yes, please state.....  
.....

5. Does your child/young person allow contact/touching?

Yes ☐ No ☐ Sometimes ☐

### Child/Young Persons Interests

6. Please tell us about your child/young person's personal likes/obsessions

.....

7. What does your child/young person like playing with?

Books ☐ Drawing/crayoning ☐ Play alone ☐

Musical games ☐ Computer/ICT games ☐ Sensory play ☐

Television/DVD ☐ Imaginative play ☐ Other .....

Further Comments...Would you bring anything in particular with you to occupy your child ?

Yes ☐ No ☐

.....

7b How much support do you feel the person accompanying your child would require when in a restricted environment ?

.....

### Fears/Obsession

8. Please tell us about your child/young person's dislikes, fears (e.g. doesn't like the colour red any foods etc)

NAME ..... HOSPITAL NO .....CLINICIAN.....

**Behaviour**

9a. Is your child/young person violent or aggressive?

Yes ☐No ☐Sometimes ☐

Comments.....

Any additional mental health disorders e.g. Anxiety ☐ or Depression ☐

9b. Will he/she be likely to attack staff or other child/young person?

Yes ☐No ☐Sometimes ☐

Comments.....

9c. Does your Child/Young Person self harm?

Yes ☐No ☐Sometimes ☐

Further Comments.....

10a. What things/events may trigger your child/young person to behave angrily, aggressively or go into a tantrum?

Sudden noise ☐Too much noise ☐Absence of structure ☐Long waits ☐Change of routine ☐Too many people ☐Environment ☐

Other.....

Further Comments.....

10b. What calms your child/young person down if he/she becomes anxious?

11. Does your child/young person use a behavioural system which is important to be carried out while in hospital (e.g. coloured spots/traffic light system and reward charts )?

Yes ☐No ☐Sometimes ☐

If yes, please state:

12. Will your child/young person tolerate being on an open ward?

Yes ☐No ☐Sometimes ☐



NAME ..... HOSPITAL NO .....CLINICIAN.....

If no please state reason and any further comments:

**Clinical Treatments**

13. Will your child/young person tolerate any of the following Medical Procedures/Experiences?

E.g. Procedures on Wards/Clinics such as:-

Weight/Height	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Temperature	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Wearing a hospital name band	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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If no photograph ID arranged	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
------------------------------	-----	--------------------------	----	--------------------------	-----------	--------------------------

Examined by doctor/nurse etc	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Taking Medicine	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Taking Tablets	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Blood pressure taken	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Attending clinics e.g. out patients	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Tolerate being in busy waiting areas	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Blood tests	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
-------------	-----	--------------------------	----	--------------------------	-----------	--------------------------

Injections	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Cannulas	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Local anaesthetic cream	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Plasters	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Going to theatre	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Wearing a theatre gown	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Having a mask on	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Has your child had sedation before	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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How did your child respond						
Going on the theatre trolley	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>

Having a cannula post theatre	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Having an x-ray?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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Having a scan?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>
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NAME ..... HOSPITAL NO .....CLINICIAN.....

Any concerns re your child post surgery/theatre

Yes ☐ No ☐ Sometimes ☐

Comments.....

Other e.g. dressings.....

Do you or your child have any mobility problems ?

Yes ☐ No ☐

Comments .....

**Education**

14. What Nursery/School/College does your child/young person attend?

.....

Contact details .....

Email address.....

15. Would it help to speak with you or the nursery, school, college to help with the time in hospital?

Yes ☐ No ☐*NB If to be admitted longer than 2 days Manchester Education School to be informed***Additional information**

16. Is your child/young person having any other treatments/tests or appointments within the hospital i.e. X-ray, EEG, dental?

Yes ☐ No ☐ Sometimes ☐

If yes, please state.....

17. Is there any further information we need to know to help you or your child/young person when in Hospital or having treatments?

Yes ☐ No ☐

If yes, please state.....

Risk Assessment required Yes ☐ No ☐**Assessment Completed Via:**Telephone ☐ Ward/Department ☐ Other ☐Parent ☐ School/Nursery/Senco ☐ Learning Disability Nurse ☐**COMPLETED BY:**

SIGNATURE ..... DATE.....

PRINT NAME ..... DESIGNATION.....

SIGNATURE ..... DATE.....

PRINT NAME ..... DESIGNATION.....