INFORMING AN AUTISM–FRIENDLY CHILDREN'S CENTRE AT CABRINI

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Principal research team:

Professor Jane McGillivray, Deakin Child Study Centre, School of Psychology, Deakin University

Ms Kelly Sherman, Children's Centre, Cabrini Health, Melbourne

Ms Clara Officer, Children's Centre, Cabrini Health, Melbourne

Ms Nicola Williams, Deakin Child Study Centre, School of Psychology, Deakin University

Dr Carmel Sivaratnam, Deakin Child Study Centre, School of Psychology, Deakin University

Professor Nicole Rinehart, Deakin Child Study Centre, School of Psychology, Deakin University

Research consultation team:

Professor Katrina Williams, Royal Children's Hospital, University of Melbourne

Ms Marijke Mitchell, Royal Children's Hospital, University of Melbourne

Ms Fiona Sharkie, Amaze (peak body for people on the autism spectrum and their families in Victoria)

Ms Deirdre Hardy, Amaze (peak body for people on the autism spectrum and their families in Victoria)

Emeritus Professor Bruce Tonge, Centre for Developmental Psychiatry and Psychology, Monash University

Assoc. Professor Avril Brereton, Deakin Child Study Centre, School of Psychology, Deakin University

Dr Tamara May, Deakin Child Study Centre, School of Psychology, Deakin University

The contribution of each member of the Research Consultation Team is acknowledged.

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EXECUTIVE SUMMARY

The principal aim of this research was to inform an Autism-Friendly Child Centre at Cabrini hospital - Malvern. Four key questions were proposed: What is known from the literature, about the needs and challenges faced by children on the autism spectrum and their families in hospital settings? What are the specific challenges faced by children with autism and their families at Cabrini? What are the views and needs of Cabrini staff who provide care to children with autism and their families? What recommendations can be made for improving the quality of the hospital experience for children with autism and their families?

An extensive review of the literature points to two key findings: First, the health care needs of children with autism spectrum disorders (ASD; autism) are substantial. Second, children with autism have additional needs in hospital settings. While there is a growing literature examining strategies to address these needs, there remains a requirement to synthesise the existing evidence and more clearly identify and understand the breadth of these needs to inform recommendations for the provision of optimal care, in particular, at Cabrini hospital.

The project design included three data collection components: consumer interviews, a survey of staff and an audit of the hospital environment and processes. We were not able to recruit participants for the consumer interviews; however, the staff survey and the participants in the hospital audit provided rich data.

Thirty-one staff members who interact with children across paediatric settings participated in an online anonymous survey (Study 2) designed to ascertain the experiences, views and training needs of current Cabrini staff with respect to children with autism presenting for health care. Key findings included widespread recognition of the importance of collaborative efforts between staff and parents; pre-admission strategies; individually tailored care that recognizes specific difficulties and strengths, and staff training. The minimization of sensory overload and hospital wait times was also emphasised.

Three parents of children with ASD and one young person with autism participated in an audit designed to gain an in-depth understanding, from the perspective of young people with ASD, of the impact of the Cabrini hospital environment, and the processes involved in attending the hospital for health care (Study 3). This component comprised an in vivo walk-through of Cabrini hospital -

Malvern and its Children's Centre. A range of issues were raised with respect to arrival, orientation, and locating the children's ward. Concerns arising within the children's ward (i.e., in the day room, play room, and overnight rooms) were also identified. Participants provided rich material demonstrating the various challenges that children with ASD may experience in the hospital environment, in particular arising from the disruption in routine and sensory and communication issues. Parent participants drew attention to the importance of streamlining hospital procedures for patients known to be on the autism spectrum, and again highlighted the importance of continuity in nursing care and collaborative efforts between staff and parents to ensure their child's needs are met. The *Hospital Passport* was well received by participants; however, concerns were expressed regarding the utilisation of this kind of resource by hospital staff.

Key recommendations for creating an autism-friendly environment, based on the literature as well as responses provided by participants in the staff survey and the hospital audit, have been made. These are presented in the following broad categories:

1. Enhancing collaboration between parent/caregivers and staff
2. Developing individually-tailored patient care plans
3. Enabling early identification of patients with ASD
4. Considering and adapting communication styles
5. Reducing common sensory triggers
6. Employing strategies to minimize and manage patient anxiety
7. Making environmental adaptations
8. Increasing staff training about ASD

While there were positive comments from parent participants and particularly from staff regarding the quality of the medical care provided at Cabrini, there were also many recommendations for improvement. Moreover, the richness of the data will allow hospital management and key staff to enhance their understanding of the experiences and challenges faced by children on the autism spectrum in the hospital setting.

The focus of this study was on children with Autism Spectrum Disorders. However, many of the issues raised would likely apply to, and the recommendations made may well enhance the experiences of other children, including those with anxiety and with intellectual and developmental delays.

CHAPTER 1: STUDY OVERVIEW

The study '***Informing an Autism-Friendly Children's Centre at Cabrini'*** was funded by the Cabrini Foundation Research Grant Round 2016-2017.

The principal aims of this research were to identify the enablers and barriers experienced by children with autism spectrum disorders who attend hospital and to translate our findings into recommendations for new, effective strategies for supporting these children and their families as they seek and receive optimal medical care.

Four key questions were proposed:

- What is already known about the needs and challenges faced by children on the autism spectrum and their families in hospital settings?
- What are the specific challenges faced by children with autism and their families at Cabrini - Malvern?
- What are the views and needs of Cabrini staff who provide care to children with autism and their families?
- Based on the evidence, what recommendations can be made for improving the quality of the hospital experience for children with autism and their families, thereby informing an Autism-Friendly Child Centre at Cabrini - Malvern?

The project design comprised a literature review and a three-part data collection strategy.

Chapter 2: Literature review.

The aims of the review were:

- to explore what is currently known about the needs and challenges faced by children with autism spectrum disorders and their families seeking general health care, with particular emphasis placed on a hospital setting; and,
- to explore the evidence base for improving the hospital experience of these children and their families.

At the outset, an overview of autism spectrum disorders is provided, with a focus on the characteristics that may be most relevant to the medical treatment arena. This is followed by a focus on health care, which is based on a comprehensive search of data bases and online resources. Consideration is given to health care utilization including hospital admission rates for this population, their additional needs in a hospital setting and the increasing recognition of the importance of addressing these needs. An overview is then provided of the strategies that have been employed and the evidence base for any such strategies that have been subject to evaluation.

The project design included three data collection components:

Chapter 3: Study 1 - Consumer interviews.

The aim of this study was to explore the hospital experiences from the perspective of children with autism and parents of children with autism who have attended Cabrini hospital at Malvern for medical care either currently or during the past 3 years. A short semi-structured interview schedule was designed for administration by telephone or face-to-face, at a mutually convenient location (Deakin University or Cabrini Hospital). This component was not achieved due to recruitment difficulties.

Chapter 4: Study 2 - Staff survey.

The aim of this study was to ascertain the experiences, views and training needs of current Cabrini staff with respect to children with autism spectrum disorders presenting to Cabrini hospital at Malvern for health care. Staff who interact with children across paediatric settings (nurses, doctors, allied health, administrative and domestic) were invited to complete an online anonymous survey delivered via the Cabrini Audit and Survey Program (CASPro) in April 2017.

Chapter 5: Study 3 - Hospital environment, processes and procedures audit.

This study was designed to gain an in depth understanding of the impact of the Cabrini hospital environment and the processes involved in attending the hospital for health care from the perspective of young people with autism spectrum. Specifically, this component was comprised of an in vivo walk-through of Cabrini hospital at Malvern and its Children's Centre by one or more volunteers on the autism spectrum (child or adolescent; not required to have been a Cabrini patient) and/or their caregivers.

Ethical compliance

Ethical approval for this project was obtained from the Cabrini Human Research Ethics Committee (CHREC) on the 06/02/17, with subsequent approval from the Deakin University Human Research Ethics Committee (DUHREC) on the 22/02/17. Potential participants (children with autism, their caregivers and hospital staff) were provided with an invitation and study Information Sheet to peruse and were given the opportunity to request further information prior to being asked to provide consent to participate. In addition to assent from any participating child or adolescent, informed consent was obtained from either parents or legal guardians on behalf of their child and for themselves. Throughout the study, it was emphasised that participation was voluntary and no individual would be identified in any report.

In compliance with Deakin University protocols, all data is securely protected, either in physical storage (a locked filing cabinet) or electronically (a secure [password protected] area of a dedicated server). The data is stored in de-identified form, with consent forms stored separately.

CHAPTER 2:

LITERATURE REVIEW

There is increased global recognition that children with autism spectrum disorders (ASD) have a range of additional needs within a hospital setting, arising from the social, communicative, executive functioning, sensory and behavioural challenges they commonly experience (Nicholas et al., 2016). Despite relatively higher levels of healthcare service utilization, hospitalizations and emergency department presentations in this group relative to unaffected children (Lokhandwala, Khanna, & West-Strum, 2012; Gurney, McPheeters, & Davis, 2006; Atladóttir, Schendel, Lauritsen, Henriksen, & Parner, 2012; Bebbington, Glasson, Bourke, de Klerk, & Leonard, 2013), it has been suggested that the health-care experience of children with ASD is often of poorer quality than that of their typically developing counterparts (Zuckerman, Lindly, Bethell, & Kuhithau, 2014). Consequently, there is a need for a deeper understanding of the barriers that children with ASD face in accessing and receiving optimal healthcare.

The aim of this review is twofold. Firstly, to explore what is already known about the needs and challenges faced by children with ASD and their families when they seek health care in general, and particularly when this is in a hospital setting. The second aim is to explore the evidence base for improving the hospital experience of these children and their families. At the outset, an overview of ASD is provided, with a focus on the characteristics that may be most relevant to the medical treatment arena. This is followed by a focus on health care, which is based on a comprehensive search of data bases and online resources. Consideration is given to health care utilization including hospital admission rates for this population, followed by consideration of their additional needs in a hospital setting and the increasing recognition of the importance of addressing these needs. An overview is then provided of the strategies that have been employed and the evidence base for any such strategies that have been subject to evaluation.

Diagnostic criteria and characteristics

Developmental disabilities are a constellation of conditions that arise from physical, learning, language, or behavioural impairments which present during early childhood and impact on the child's day to day functioning (Centers for Disease Control and Prevention; CDC, 2017). These include attention deficit hyperactivity disorder, intellectual disability, learning disorders, cerebral palsy, autism spectrum disorders, as well as a range of speech and sensory difficulties and other developmental delays, with one or more reported in approximately 15% of children (Boyle et al., 2011).

Autism spectrum disorders are characterised by marked and persistent difficulties in social interaction and communication, as well as restricted and repetitive interests, thoughts and patterns of behaviour. The symptoms of ASD are present from early childhood and while they may change with development, they generally persist in some form into adulthood. The term 'spectrum' captures the wide variation in the range and severity of the characteristics and difficulties experience by individuals with an ASD. While there is no single indicator of ASD and individuals can vary markedly from one another in presentation and symptom severity, individuals commonly present with one or more of several characteristics across social communicative and behavioural domains.

According to the criteria specified in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; APA, 2013), social communication impairments occur across different contexts and manifest as deficits in: i) social-emotional reciprocity; ii) non-verbal communication; and iii) deficits in relationship development, maintenance and comprehension. Restrictive, repetitive patterns of behaviour manifest as deficits in two of: i) stereotyped or repetitive movements, speech or use of objects; ii) inflexible adherence to routines, insistence on sameness or ritualized patterns of verbal or non-verbal behaviour; iii) fixated interests that are distinguished by abnormal intensity or focus; and iv) hyper- or hypo-sensory reactivity or atypical interest in sensory aspects of the environment (American Psychiatric Association [APA], 2013).

Communication indicators may include the absence, delay or unusual presentation of verbal and nonverbal communication. Children with ASD may not respond to their name and may show selective hearing – responding to certain sounds but ignoring the human voice. They may have limited or absent expressive language or may show unusual patterns of language (e.g., echolalia or repetitive speech). Further, they commonly experience difficulties understanding the subtleties of language including non-literal vocabulary and non-verbal components of communication. Their interpretation is often very literal or 'black and white' and they may answer general or open ended questions in a very limited way.

Social skills and play indicators may include looking away when someone is speaking to them, not returning a smile, a lack of interest in peers, not wanting to share interests or play with others, limited, unusual or ritualistic play (repetitive spinning or lining up) and often appearing to be in their own world. Although language and social ability may improve with age, aspects commonly remain unusual and distinct from that of typically developing peers.

Behavioural indicators may include unusual attachments and interests; unusual and repetitive motor movements; strong preference for routines and familiar environments; and “meltdowns” or tantrums (sometimes involving aggression or self-injury) that may appear to be inexplicable or may arise from difficulty coping with certain sensory stimulation, social interaction, or novel situations and change. Wandering behaviour and running away is also common among children with ASD, with reported rates of 37.7% among children with ASD and intellectual disability and 32.7% in children with ASD without intellectual disability (Rice et al., 2016). Examples of sensory indicators include the use of peripheral vision to examine objects or persons, excessive smelling or touching of objects, preoccupation with moving parts, and a fascination with specific sounds, textures, light or colours. An adverse reaction may occur when these opportunities are taken away or otherwise changed. Hypersensitivity and adverse responses to other sensory experiences (across auditory, olfactory, visual, taste, and touch) are also common, as are unusual reactions or apparent indifference to temperature and pain. In addition, individuals with ASD may not hear, feel or see things simultaneously, due to delayed or single channel processing (APA, 2013).

Prevalence and gender ratio

The prevalence of ASD varies depending on the source of data, the age of the individuals screened and the criteria for inclusion in the sample. It is well documented, however, that rates of diagnosis have increased globally (Matson & Kozlowski, 2011; Taylor, Jick, & MacLaughlin, 2013). According to the Australian Bureau of Statistics (2017) (based on data derived from the Survey of Disability, Ageing and Carers; SDAC, 2015), there were 164,000 Australians with autism in 2015 (approximately 0.68%), representing a 42.1% increase from the 115,400 estimated in 2012. More recently the prevalence of ASD in Australian children has been estimated to be 3-4% of the population (Bent, Barbaro, & Dissanayake, 2017; May, Sciberras, Brignell, & Williams, 2017). As noted by Williams, Woolfenden, Roberts, Rodger, Bartak, and Prior (2014), among other factors, increases in prevalence likely reflects changes to the diagnostic criteria, increased awareness and knowledge of ASD, and enhanced early detection and diagnoses, including in milder cases.

Skewed gender ratios indicating that there are approximately four times the number of boys diagnosed with ASD than girls have been consistently reported in Australia (Australian Bureau of Statistics, 2017, Survey of Disability, Ageing and Carers (SDAC, 2015) and internationally (CDC, 2014). These ratios have, however, been challenged on the basis that the diagnostic criteria have been derived largely from research on males and are thus biased toward the male presentation (Dworzynski, Ronald, Bolton, & Happé, 2012) and with common screening instruments less reliable for identifying ASD in girls (Andersson, Gillberg, & Miniscalco, 2013; Rivet & Matson, 2011). A recent systematic review indicated that the gender ratio was 3:1 (Loomes et al., 2017).

Although there is no single known cause of ASD, strong genetic links have been identified, with twin studies indicating that heritability is between 37-90% (APA, 2013). ASD can be diagnosed in combination with one or more other developmental disabilities, mental or behavioural disorders (APA, 2013), as well as across the range of levels of intelligence. According to the Centre for Disease Control and Prevention data (Christensen et al., 2016), for example, in 2012 an IQ ≤70 was present in 32% of diagnosed 8 year olds, 24% had an IQ between 71-85 and 44% had an IQ >85.

Cognitive theories and characteristics

Three key underlying cognitive theories have been explored in explanations of ASD and its cognitive characteristics. Each of these have implications for the way children with ASD experience the hospital environment, particularly with respect to difficulties with information processing, communication (Brown & Elder, 2014) and coping. The **theory-of-mind** account (Baron-Cohen, Leslie, & Frith, 1985) suggests that individuals with ASD have an impairment in the development of social cognition; they fail to understand that other people have independent mental states. They thus may not take into consideration that others may think differently to them, and may hold their own motivations and points of view. This can lead to confusion and misunderstanding and may manifest in a lack of empathy, pragmatic issues with language and difficulty forming and maintaining relationships.

The **executive function** theory (Pennington & Ozonoff, 1996) suggests that individuals with ASD have difficulties in planning, organizing, multi-tasking, decision making, and inhibiting automatic behaviours or impulses. Deficits in executive function also make it difficult to switch attention from one activity to another, cope with shifts in activity and alter thinking following the learning of a concept. According to the theory of **weak central coherence** (Happe & Frith, 2006), individuals with ASD have different methods of perceptual-cognitive processing. In particular, they are inclined to perceive and process certain specific features of incoming information at the cost of an overall message and contextual meaning. Not being able to see the big picture, can lead to ambiguity, misunderstanding and difficulty coping with the detailed information they may well receive in a hospital setting. Central coherence and perfectionistic characteristics will likely mean that time allowances will be needed for the child to achieve readiness to move on from one medical/treatment task to another. Timed tasks and some multi-component medical procedures may be particularly problematic.

In considering the impact of cognitive abilities and characteristics, it is important to note that children with ASD are likely to show considerable breadth and scatter in ability. For example, some individuals will be better than others at understanding visual information, such as when pictures of the children's ward or visual behavioural scripts and timetables are used to prepare them for their time in hospital or a medical procedure. This visual communication material must also take cognitive level into account so that it is comprehensible to the particular child. It is further important to note that other characteristics such as visual/motor and fine and/or gross skill levels might affect the hospital experience and ease of participation and outcomes from some medical assessments. Most often, parents are well aware of these individual characteristics of their child and will be the best source of advice about how best to plan and prepare their child for elective admission or for a specific medical procedure, including practice experiences.

Comorbidity

In addition to the wide variations in clinical presentation, symptom severity, and cognitive ability (APA, 2013), ASD commonly occurs with a range of other medical, behavioural or psychiatric conditions that may compound core symptoms and increase the complexities around adjustment and behaviour management. According to Simonoff et al. (2008), as many as 70% of children with ASD also meet diagnostic criteria for another disorder, with over 40% having two or more comorbid disorders. There are indications that close to two thirds of children with ASD also have an intellectual disability (Leonard et al., 2011) and ASD frequently presents with other developmental disorders such as Attention Deficit Hyperactivity Disorder (Green et al., 2015; see also review by Leitner, 2014).

People with ASD also commonly display neurological symptoms such as sleep disturbance, motor disturbance and epilepsy (Jeste, 2011). For example, according to Goldman, Richdale, Clemons and Malow (2012), sleep problems affect up to 80% of adolescents with ASD. In their systematic review, Woolfenden, Sarkozy, Ridley, Coory, and Williams (2012) reported that the percentage of individuals with epilepsy was 1.8% and 23.7% respectively in studies of people with ASD without and with an intellectual disability, well exceeding rates in the general population. Although the evidence is conflicting, children with ASD are also reported to have a range of gastrointestinal disorders (Wang, Tancredi, & Thomas, 2011; Buie et al., 2010). In addition, they have high rates of feeding issues such as oral aversion, selective eating, ritualistic eating habits and other non-functional mealtime routines (Geraghty, Depasquale, & Lane, 2010). Sensory aversions across the domains of sight, taste, texture, sound and smell are common and may contribute to feeding challenges (Cermak, Curtin, & Bandini, 2010; Nadon, Feldman, Dunn, & Gisel, 2011).

Psychiatric comorbidity is also common in individuals with ASD, with approximately 70% meeting criteria for another mental disorder and approximately 40% meeting criteria for two or more comorbid mental disorders (APA, 2013). In comparison to their typically developing peers, for example, adolescents with ASD may be vulnerable to depression and suicide (e.g., Pouw, Rieffe, Stoskmann, & Gadow, 2013; Storch et al., 2013). Anxiety is highly prevalent in children with ASD (Van Steensel, Bögels, & Perrin, 2011), with the rates of occurrence as much as two times higher than in the general paediatric population (Costello, Egger, & Angold, 2005). Anxiety appears to be especially prevalent when regular daily routines are disrupted or when individuals confront a novel situation or unfamiliar environment. Anxiety and depression are likely to compound the other difficulties experienced by children with ASD, reducing their opportunities and well-being. They are thus critical areas for intervention.

Interventions

A central focus of interventions for children with ASD is on early recognition and the initiation of efforts to reduce the negative impacts of core features and associated secondary issues (Roberts & Williams, 2016), while harnessing individual strengths and preferences. For example, many children with ASD have a strong preference for visual stimuli, particularly electronic screen media. The use of visual teaching materials may thus be important in the design of educational programs for these children.

While there is no medication to manage the central deficits of ASD, many children and adolescents with ASD are medicated for the management of challenging behaviours and comorbid conditions (Broadstock, Doughty, & Eggleston, 2007). For example, in a study of 2,853 children with ASD, Coury et al. (2012) reported that at least one psychotropic medication was taken by 11% of children aged 3-5 years, 46% of children aged 6-11 years and 66% of children aged 12-17 years. It is also the case that many children with ASD receive a variety of vitamin/naturopathic/dietary supplements. In the context of health care, it is essential that current medications and supplementary treatments are known as they might interfere or adversely interact with other medications, including anaesthetics.

Interventions commonly involve an analysis of the antecedents (triggers) and the functions of any undesirable behaviour. For example, in attempting to address highly repetitive behaviours, there has been a focus on determining whether it is driven by naturally occurring internal motivation and reinforcement, or whether it is a behavioural response to the stress experienced in facing everyday challenges, such as change in routine. In this sense it would represent an attempt to relieve anxiety through repetition and a sense of control (Boyd, McDonough, Rupp, Khan, & Bodfish, 2010). There are now a number of good reviews of evidence-based interventions to inform practice (see for example, Roberts & Williams, 2016; Prior & Roberts, 2012; Schreibman et al., 2015; Weitlauf et al., 2014; Wong et al., 2014).

In addition to individualized interventions, there have been widespread efforts to create or modify environments to cater for the needs of individuals with ASD, thereby minimizing the stress they may experience in their day to day lives, as well as in unexpected situations that may arise from time to time. This includes the promotion of increased community understanding and acceptance of ASD, as well as more specific efforts, such as attempts to create 'autism friendly environments' in schools, museums, playgrounds, and health care facilities.

For further background information on ASDs, the reader is referred to Brereton and Tonge (2017). These authors provide a comprehensive, accessible and current overview of ASD, written as an update for General Practitioners.

Health care needs of children and adolescents with ASD

The focus of the remainder of this review is on the health care needs of children and adolescents with ASD. Following an overview of what is known about health service utilization in this population, a focus will be placed on their specific needs in health care settings and on the existing research that can be used to inform recommendations for strategies and resources to support the delivery of high quality health care to this group. The literature was identified through a comprehensive search of databases, including Pubmed and Medline, with a secondary search conducted from the reference lists of those found and including some grey literature identified from a search of the internet.

Elevated health care utilization

In addition to the apparent increase in the prevalence of ASD, the comorbidities frequently associated with its core characteristics point to disproportionate health care needs and an increasing likelihood that a young person with ASD will present for health care. There is evidence that individuals with ASD have higher overall rates of health care service utilization in terms of frequency and duration of visits than both their typically developing peers (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Cummings et al., 2016; Gurney et al., 2006; Leslie & Martin, 2007; Liptak, Stuart, & Auinger, 2006; Wu, Kung, Li, & Tsai, 2015) and children with chronic health conditions (Liptak et al., 2006; Wu et al., 2015). For example, despite the limitations of self-report data and the lack of verification of ASD diagnosis, Gurney et al. reported from a large (n=100,000) cross sectional USA survey (the National Survey of Children's Health; 2003 -2004) that children with ASD had significantly higher (p<.001) mean physician visits for preventive care, non-emergency care and hospital emergency care than children without ASD. Similarly, according to Wu et al. (2015), annual physician visits were an average of 14.2 more likely for children with ASD. These children were also more likely to visit the emergency department (OR=1.12, P<.05) or be hospitalized (OR=1.48; P<.05) than children without ASD.

Hospital admissions and emergency department presentations

Presentations to the emergency department (ED) may be especially likely (Gurney et al., 2006) due to the high rate of accidents and injuries reported in children with ASD. For example, in a comparison of 1,610 such children with 91,571 typically developing children undertaken by McDermott, Zhou, and Mann (2008), those with ASD were 20% more likely to be hospitalized for injuries, with a notable elevation in the frequency of head and neck injuries, poisoning and self-injury. In a more recent pilot study comparing emergency department visits in a paediatric hospital in Memphis, USA, Casey et al., (2015) reported significant differences between children with ASD and non-ASD children in presenting complaints, with increased neurological conditions, such as epilepsy, and general medical complaints indicating more frequent and possibly exaggerated somatic response in the children with ASD. According to Lunsky, Paquette-Smith, Weiss and Lee (2015), 13% of a sample of 396 parents in Ontario, Canada, reported that their child with ASD had used at least one emergency service (ED's, paramedics or police) in a two month period, with 23% of these presentation involving restraint or sedation.

Other studies show that general hospital admissions are also increasing (Nayfack et al., 2014). Children with ASD are more likely to be hospitalized and to spend more time in hospital than their typical peers in the USA (Lokhandwala et al., 2012), in Denmark (Gurney et al., 2006; Atladóttir et al., 2012), and in Australia (Bebbington et al., 2013; Williams et al., 2005). In a study of hospitalization data in Western Australia, Williams et al. (2005) reported that 64% of 191 children with ASD and ID were hospitalized in the first 5 years of life, compared with 48.2% of 238,317 typically developing children. In a more recent prospective cohort study, Bebbington et al. (2013) reported an increased risk of hospitalization for children with ASD and/or ID up to 10 times greater than in unaffected children. Comorbid intellectual disability significantly compounded the risk.

Health care expenditure

Not surprisingly, expenditure on health care is also significantly inflated (Croen et al., 2006; Gurney et al., 2006; Liptak et al., 2006; Tregnago & Cheak-Zamora, 2012; Wu et al., 2015). Inflated costs appear to be incurred across total health care, total outpatient care, physician visits and prescription medicines (Barrett et al., 2012).

Satisfaction with care

Despite inflated presentation for health care and a corresponding increase in incurred costs, this regretfully does not always appear to correlate with high ratings of satisfaction with the care received (Carbone et al., 2013; Kopecky, Broder-Fingert, Iannuzzi, & Connors, 2013), nor with enhanced health care and outcomes (Strunk, Pickler, McCain, Ameringer, & Myers, 2014). For example, in a multicomponent study of health care quality in a large USA sample, Zukerman at al. (2014) reported that children with a diagnosis of ASD receive poorer health care than children with special health care needs and no diagnosis of ASD.

To determine the extent to which the needs of children with ASD were being met in emergency departments, Nicholas et al. (2016) conducted focus groups with 16 parents, 37 clinicians and 7 administrators from emergency departments of two children's hospitals in Canada. Overall, participants maintained that the needs of children with ASD were not being fully met in this environment. In another qualitative study of the experiences of 22 Canadian families of hospitalized children with ASD, negative experiences arising from rigidity and inflexibility in some settings were reported (Muskat et al., 2015).

In a recent Australian online survey conducted by Amaze, the peak body for people on the autism spectrum and their families in Victoria, feedback about hospital experiences was provided by a sample of 222 mostly parents and carers of children with autism, as well as from a small number people on the spectrum (Stagles, 2016). In 42.2% of cases, the child had attended for a scheduled visit, with 58.9% having attended in the context of an emergency. While 59.7% of respondents ranked the experience as 'excellent' or 'good', 25.1% non-the-less provided ratings of 'poor' or 'terrible'. Furthermore, while most participants reported that hospitals supported the use of strategies which helped the young person during their visit, this was not so in 41.4% of cases.

In response to the increasing prevalence of ASD and compounded by elevated health care needs in this population, there has been a corresponding increase in the demand for autism-friendly health care environments. There are now numerous publications on the development and evaluation of environmental and procedural modifications to enhance the provision of best practice health care and the health care experiences of children with ASD and their families. A number of practical recommendations for supporting paediatric patients with ASD in hospital settings are also now available (see for example, Pratt, Baird, & Gringras, 2012; Scarpinato et al., 2010).

There remains a need for health care providers to work toward improved service delivery to children with ASD. There is also a need for continued research to provide an evidence base for the approaches taken to address the additional needs arising from the core characteristics of ASD and associated comorbid conditions and to minimize potential barriers to health care for these children.

Collaborative approach to care through involvement of the parent/caregiver in the development of individually-tailored patient care plans.

The value of collaborative care between medical staff and family members and the importance of the information obtained to the provision of individualized care to young people with ASD has been emphasised (Bultas, 2012; Davignon et al., 2014). Enabling this informed planning in a hospital setting, requires that systems are in place for the early identification of a child patient with ASD and communication flow between parent/caregivers and staff, and between staff.

Communication and collaboration with parents

The important necessity of partnering with parent/caregivers and acknowledging them as expert informants and advocates for their child's needs has been widely acknowledged (e.g., Muskat et al., 2015; MacKenzie, Abraham, & Goebel, 2013). Parents/caregivers are able to provide critical information such as the triggers of challenging behaviour in their children (Strauss et al., 2015; Nicholas et al., 2016), as well as strategies that may be helpful to assist them to cope in stressful situations (Nicholas et al., 2016; Thompson et al., 2014). Parents can advise on their child's profile including intellectual, mental health and sensory needs and the best way to communicate with them and they are also usually able to serve as two way translators of information between their child and health care staff (Vaaz, 2010).

As noted by MacKenzie et al. (2013), parents have described having to repeat information to successive health care professionals as a stress factor and identified the need for better communication strategies across hospital settings and health care staff. The dissemination of parent-informed individualized care plans may assist with the transfer of information. It is important to note the possibility that some parents may not readily communicate or engage in collaboration due to being embarrassed by their child's behaviour and experiencing high levels of stress when attempting to explain to staff who may not understand, or who may regard the child as non-compliant and the parent as lacking in control (Ling, Mak, & Cheng, 2010). In most cases, however, parents are very willing to partner with health care providers and alert them to their child's individual care needs. It is of course ideal if this can happen prior to admission, so that planning can occur for care that is tailored to minimize anxiety, while maximizing the quality of health assessment and intervention.

Pre-admission planning

Advanced knowledge of an individual child's needs and challenges and an opportunity to consult with their family enables preparation and delivery of individualized care by health care providers. Yet hospital systems do not always facilitate this. For example, participants in the study by Davignon et al. (2014) reported inconsistent practices and a lack of organizational support to enable early identification and informed planning for a child patient with ASD. A lack of clear processes for information sharing between staff was also identified.

The value of a medical record with a unique identifier that enables a patient with a diagnosis of ASD to be identified prior to admission has also been emphasised (Thompson et al., 2014). While not possible with emergency admissions, in the case of admission to hospital for planned health care or attendance at outpatient clinics, pre-admission/attendance planning allows both the hospital, the family and the young person with ASD the opportunity to prepare. The value of pre-admission planning involving parents/caregivers has been well endorsed in the literature, (e.g., Muskat et al., 2015; Pratt et al., 2012). In Pratt et al., for example, positive informal feedback was provided from health care providers and family in response to the implementation of an intake survey/checklist to identify and attempt to accommodate any unique needs and challenges in the care they provide.

Kopecky et al. (2013) developed a Parent/guardian Survey for assessing the needs of ASD patients, including questions such as 'How does the individual express their needs?' 'What is the best way for medical staff to examine this individual?' 'Will the individual tolerate wearing an ID band on their wrist?' This appears to be a useful survey for collecting a range of relevant information. There are also a number of existing instruments, such as The Psychosocial Risk Assessment in Paediatrics (Staab, Klayman, & Lin, 2014) that may be able to be adapted to elicit relevant information from parents about their child with ASD prior to a hospital visit.

The importance of pre-admission planning was emphasised by Blake (2010) who suggested that the child attend for an individual assessment prior to the hospital visit, with an emphasis on the child's triggers for challenging behaviours, as well as their strengths and coping behaviours. According to Blake, this pre-assessment could enable a bypass to the usual admission procedure. In addition, the information could be especially important as the child moves from admissions to other areas of the hospital.

The focus group participants in Nicholas et al.'s (2016) study also recommended that standardized assessments be administered at registration, such as a brief checklist or screening tool that identified the individual's needs, in order to optimize their comfort and care. Participants emphasised that such an instrument needed to be brief enough that it did not add to parental stress or delay the process of triage and treatment and that it be electronic in format so that the data can be easily accessed on future occasions, and easily disseminated to other staff across departments.

Perioperative settings

The importance of communication with parents has been demonstrated in findings from studies on the preparation of children for surgery. Perioperative settings are particularly confronting for children with ASD who need to undergo surgery and challenging behaviours commonly occur in this setting (Kopecky et al., 2013). A number of hospitals have implemented behavioural approaches to the management of these behaviours (e.g., McGonigle, Migyanka, Glor-Scheib et al., 2014a). Although there is a growing evidence base for preoperative management practices for children with ASD, it was concluded from a systematic review by Koski, Gabriels and Beresford (2016) that the dominance of case studies and studies with weak methodological design limits the conclusions that can be drawn. Nonetheless, and importantly, the strategies that appear to be the most useful involve communication and collaboration with caregivers regarding the child's specific needs relevant to their hospital experience, the use of individualized plans to ensure staff are aware of this information and support for addressing these needs via environmental modification.

Of note, one of the better studies identified in the review was an evaluation via retrospective audit of 59 children with ASD receiving day surgery in a hospital in Adelaide across a four year period undertaken by van der Walt & Moran (2001). While now quite dated, the findings match those of more recent studies. The authors reported that routine early communication with the family via a scripted telephone call to obtain information about the child and parental expectations, together with flexible admission procedures to minimize wait times were key factors to preparing children for the pre-operative process. In addition, the involvement of a parent in all stages from induction to the recovery phase and the availability of a quiet room were identified as beneficial.

Thompson et al. (2014) report on a more recent prospective study of 43 children with ASD who were undergoing a scheduled surgical procedure requiring an anaesthetic. In this study, designed to optimize practice, parents received a pre-operative phone call comprised of questions drawn from the literature to determine information relevant to assisting children with ASD to cope with stressful events. For example, behaviours that signal that their child is having difficulty coping and whether their child would likely benefit from access to a picture chart explaining the steps and procedures to familiarize them with what will occur. Parents were encouraged to nominate special interests that may be able to be satisfied through access to the hospital toy box and also to bring the child's favourite toy or electronic device that may assist them to cope with their anxiety. Caregivers were interviewed post-surgery, with themes coded to identify their views on the hospital experience for their child. Families were appreciative of the efforts taken by staff, who appeared able to successfully liaise with families pre-operatively to ascertain the needs and to identify stressors (potential and actual) for the child patient with ASD.

Development of individual care plans

The use of individualized care plans are an endorsed strategy to improve hospital care for children with ASD. While care plans differ in content, they generally include a range of relevant information about the child with ASD including their strengths and difficulties, such as their sensory sensitivities, style of communication, triggers of anxiety and strategies that may be helpful in the management of their anxiety and associated behaviours. As suggested and implemented by Thompson et al. (2014), there is merit in a functional determination of developmental level in assessing capabilities and needs, rather than relying on the child's age, diagnosis or broad descriptors of 'mild' or 'severe'. Care plans are ideally attached to the child's medical chart, which accompanies the child across hospital settings, and enables all staff ready access to key information.

In a US study undertaken by Broder-Fingert et al. (2016), parents who used autism specific care plans reported significantly greater overall satisfaction with the hospital experience and in terms of staff recognition of their child's autism-specific needs, than parents who did not use care plans. The care plans specified the patient's autism specific needs across expressive and receptive communication, social and pragmatic concerns and safety, and were made available to parents prior to admission either on line or in hard copy format. The plans were uploaded into the patient's electronic medical record. Accessing the care plans was tracked electronically to monitor use according to staff category. Interestingly, the plans were accessed most commonly by nursing staff and least often by attending physicians.

Clearly there is a need to ensure that health care providers are given advanced understanding of the needs of children with ASD and their families and that protocols are developed to accommodate their unique characteristics and promote best quality and positive health care experiences. A form of individual care plan, known as *My Hospital Passport*, has been developed by the National Autistic Society in the UK for people on the autism spectrum (Well, 2014). A request is made of hospital staff to consult the passport before assessing the individual or carrying out any interventions. It is designed to be kept with the patient's notes, and returned to the patient/family upon discharge. The passport includes information under the headings – personal information; how the individual communicates and how they would like staff to communicate with them; how the individual experiences and communicates pain; things that distress the individual and how these can be avoided; medical and medication history and other things that may be relevant, such as rituals, special interests or sensory needs. See http://www.autism.org.uk/about/health/hospital-passport.aspx for access to the passport and helpful guidance notes.

Managing anxiety through effective communication and strategies, such as environmental modifications, that minimize sensory triggers.

Anxiety in children with ASD

While most children find visits to a hospital or other health care setting and exposure to medical equipment and procedures to be anxiety provoking, these can be especially challenging for a child with ASD and may result in high levels of anxiety and the possibility of challenging behaviours.

Anxiety is particularly likely to arise in situations where there is a deviation from the child's regular routine and a need for them to confront unfamiliar and unpredictable environments, people and demands (Chebuhar, McCarthy, Bosch, & Baker, 2013). Long and unpredictable waiting times (McGonigle, Venkat, Beresford, Campbell, & Gabriels, 2014b; Davignon et al., 2014; Stagles, 2016), unexpected changes, such as to the order of events, procedures or the staff member present (Johnson et al., 2014) and requirements for transition through different activities and different areas of the hospital (Muskat et al., 2015), can be especially problematic for many of these children. Anxiety may also arise from a requirement to cease a preferred behaviour or activity, the absence or withdrawal of a calming or distraction object, sensory sensitivities and from communication and comprehension difficulties.

Approximately 25% of participants in the Amaze survey (Stagles, 2016) listed their child's anxiety as a dominant concern when they visited hospital. Anxiety was reported to manifest in a variety of ways, ranging from constant question asking and reassurance seeking, to full-blown behavioural 'meltdowns' (Stagles, 2016).

Some may experience mild to moderate anxiety and distress that may present as agitation, while others will experience a high level of anxiety that may lead to the individual being unable to remain in the environment. If the person is unable, or is not supported, to regulate their emotions they may experience acute anxiety that may trigger emotional outbursts, aggression and combativeness (e.g., hitting, kicking, biting, property destruction), self-injury (e.g., head banging, self-induced vomiting), hyperactivity and non-compliance with medical procedures (Johnson & Rodriguez, 2013). These responses may result in the need to use force to examine or treat the child, and can place staff, the child and other patients at risk of injury (Debbaudt, 2009).

In their survey of Canadian parents, Kopecky et al. (2013) reported that safety concerns while their child was in hospital were expressed by 50% of respondents. Identified concerns included their child wandering away or bolting (65%), or displaying self-injury or aggression (15%), pica (10%) and pulling out IV tubing (10%). In Muskat et al. (2015), parents specifically reported difficulties associated with the involvement of multiple heath care professionals, especially when they congregate in the child's room. As explained by one parent, this signals to their child that something unpleasant is imminent and that the additional people may be there to restrain them.

The challenges faced by health care staff in meeting the needs of individuals with ASD presenting for health services have been well acknowledged (McGonigle et al., 2014b; Sakai, Miller, Brussa, Macpherson, & Augustyn, 2014). Particular concerns have been raised by health care practitioners, predominantly nurses, regarding the ineffective management of challenging behaviours of children with ASD in health care settings (Rhoades, Scarpa, & Salley, 2007; Weil & Inglehart, 2010) and it is widely acknowledged that challenging behaviours in these children can cause elevated stress in health care providers (Carbone et al., 2010; Scarpinato et al., 2010).

Strategies to manage anxiety and minimize risk of challenging behaviours and safety concerns

The modification of environmental triggers and enhanced attention to sensory sensitivities and communication needs are key strategies for health care providers to minimize anxiety in patients with ASD. The prevention and management of challenging behaviours is central for patient wellbeing and in order to avoid procedural cancellations, patient restraint, and staff injury. A range of specific suggestion are provided in the literature to both guide the delivery of health care and to prevent and/or address anxiety and the possibility of challenging behaviours.

Individuals with ASD may rely on a variety of toys and devices to assist them to manage their anxiety, cope when they are overwhelmed, and focus their thinking. They may fiddle with something tactile like a squeeze stress ball or a lump of plasticine/putty, or they may use a fidget spinner device. It is important that children be permitted to access their preferred stress reducing techniques.

With regard to minimizing challenging behaviours, emphasis has been placed on the importance of analysing the function of the child's behaviour in order that strategies can be put in place to assist them to cope in more adaptive ways (Johnson et al., 2013). Bultas, Johnson, Burkett and Reinhold (2016) highlight the importance of recognizing triggers, while Johnson et al. (2012) recommend a focus on early signs that the child is becoming overwhelmed so that strategies can be implemented prior to further escalation. MacKenzie et al. (2013) emphasise the importance of medical staff paying attention to the child as a whole including gaining some understanding of possible aetiologies of somatic symptoms, emotional reactions and behaviours, thus allowing implementation of appropriate behaviour management strategies, including the management of environmental contingencies. Clearly staff would require training in order to be able to implement such strategies. Staff training needs are addressed later in this review.

Features of the physical environment

Like any other building, healthcare settings are comprised of a range of structural and design features that may present a challenge to a child with ASD. Particular patterns, surfaces, colours and spatial configurations (such as hallways) may contribute to agitation and anxiety due to their heightened sensory sensitivities (Shell, 2016). Other aspects of the hospital environment, such as the sounds, smells, tactile sensations, bright lighting, colours, crowding and the pace of activity can also be overwhelming to a child with ASD (Muskat et al., 2015). According to Kopecky et al. (2013), loud noise was identified as a sensory difficulty in 39% of cases, with tactile (25%) and food (15%) sensitivities also identified. Similar findings were evident from the Amaze survey, with a range of sensory issues, such as hypersensitivity to florescent light, sounds (e.g., beeping, alarms, and sirens) and being touched commonly reported as issues by Australian parents (Stagles, 2016). Emergency departments are especially challenging and likely to result in sensory overload (Scarpinato et al., 2010; Johnson, Bekhet, Robinson, & Rodriguez, 2014; Vas, 2010), thereby compounding the individual's anxiety and increasing the risk that self-stimulatory and challenging behaviours will be triggered.

Shell (2016) published an online article that draws on both research and experience to emphasise the importance of a universal design approach that supports, in particular, the sensory regulation of people with ASD. In addition to providing a number of recommendations, Shell provides an argument for '*why buildings for autistic people are better for everyone*'. See: http://www.megroup.com/blog/better-buildings-for-everyone/.

A recent report entitled *Building autism friendly environments: Promoting meaningful access and participation for all* has been submitted by Amaze (2017) to the Senate Community Affairs References Committee Inquiry into the Delivery of Outcomes under the National Disability Strategy

2010-2020 - building inclusive and accessible communities. In addition to useful recommendations for change to standards and policy, the submission includes case studies demonstrating how the built environment can be modified to enhance inclusion and accessibility for autistic people. Importantly, in line with Shell (2016), it was emphasised in this submission that environmental adaptations and tools are likely to have benefit for other individuals, such as children with other disabilities and anxious children. See: http://www.amaze.org.au/2017/05/building-autism-friendly-environments-amaze-submission/

Additionally, Simons (2016) provides a *Checklist for Autism-Friendly Environments* that supports the recommendations on the physical environment in the NICE guidelines on Autism spectrum disorder. See: http://www.hirstwood.com/wp-content/uploads/2016/11/Checklist-for-Autism-Friendly-Environments-September-2016.pdf

Current literature highlights the importance of providing a low-stimulation sensory environment (Kopecky et al., 2013). This includes minimizing noise from machines, pagers, and the like and keeping lights low (Scarpinato et al., 2010), with low lighting suggested by 18% of the participants in Kopecky et al. (2013). A range of recommendations for lighting have been put forward in a detailed online document by Mohamed (2014) from the New York City School Construction Authority, including using indirect or filtered light and minimizing use of fluorescent lights due to their flicker and audible hum. See: https://www.slideshare.net/HusseinMohamedPE/autism-spectrum-disorder-asd-education-environment-54657082

There is some evidence on colour preferences in autism. For example, in a study by Grandgeorge and Masataka (2016), boys with ASD were significantly less likely than typically developing boys to prefer yellow and more likely than typically developing boys to prefer green and brown colours. There is also some research from the University of Kingston recommending the use of an autism friendly palette, avoiding patterns, and the use of colours to distinguish walls, floors and furniture to make it easier to navigate. It was also suggested that design features, such as proxemics, may be helpful to maximize comfort. For example, curved walls, and circulation spaces, rather than ‘corridors’ may be advantageous to minimize running opportunities. See: http://www.autism-architects.com/wp-content/uploads/downloads/2012/06/MLA-Presentation-November-2010-low-res-pdf.pdf

As suggested in the Amaze (2017) report, colour coded sensory maps may be a useful addition to enable people with ASD and their families to enable them to avoid or plan for high sensory environments and locate low sensory environments within a particular setting. These may be provided in hard copy or electronic format in situ or on line, so that the individual can become familiar with the layout prior to the visit.

Environmental recommendations also include the provision of a smaller, quieter room in which the child can wait or use to calm down. This room can be a place where the child can go to avoid sensory stimuli such as noise and excessive activity, while supporting specific sensory seeking and calming behaviours through access to electronic hand held devices, toys, games and other distractors and sensory boxes from which a patient can select options such as squeeze balls (Bultas, 2012). In Kopecky et al.'s (2013) sample, 35% reported that access to music, puzzles and videos were helpful.

Medical procedures

Standard diagnostic and intervention procedures, such as physical examinations and other procedures involving touch may be perceived by individuals with ASD as invasive and unpleasant (McGonigle et al., 2014b; Giarelli et al., 2014). Procedures such as blood pressure monitoring, venepuncture, intravenous placement, injections and the like may be extremely difficult for children with ASD (Giarelli et al., 2014; Scarpinato et al., 2010; Souders, Freeman, DePaul, & Levy, 2002), especially if they have previous medical experience that has been unpleasant. Examinations of the ears and throat, drawing blood and injections, blood pressure measurement and examination of the genital areas were identified as the types of physical examinations that caused the most difficulty for children with ASD (Kopecky et al., 2013). Further, it was reported that 25% would not be comfortable wearing a hospital gown, while as many as 40% would likely not tolerate an identification bracelet (Kopecky et al., 2013). According to Thompson et al. (2014), staff reported that behavioural difficulties in children with ASD that exceeded those that occur with the average child patient are precipitated by factors such as having vital signs taken, having a mask placed over their face, waking up post operatively with unfamiliar and invasive equipment (monitors, intravenous tubes, blood pressure cuff), as well as the noise in the post-anaesthesia recovery area (crying children, monitoring equipment and other machines).

Kopecky et al. (2013) report that explaining each step involved in a physical examination as it was happening was considered to be the best option by 50% of respondents, with 37% suggesting that the patient be allowed to examine the instrument before the event, a suggestion also made by Chebuhar et al. (2013). Modelling the procedure on a trusted adult, was also suggested by participants in Kopecky et al.'s study. Bultas, Johnson, Burkett, & Reinhold (2016) recommends that health care professional should start with essential aspects of the procedure, while use distracting or relaxation techniques such as deep breathing exercises. If the individual engages in ritualistic behaviours, it is suggested that they be permitted to do so, providing they are safe behaviours, as they may serve as coping mechanisms (Johnson et al., 2012). Where possible, allowing time for transition between procedures or parts of a procedure is suggested (Bultas et al., 2016). On the basis that children may be less likely to respond to reassurance, coaxing or verbal explanations, it was also suggested that the provision of tangible rewards for progressing through the stages may also help, particularly with compliance in the future (Bultas et al., 2016).

As previously emphasised, the differences between children with ASD signals the need to individualize approaches. According to Muskat et al. (2015), for example, some individuals like preparatory strategies, such as detail about what is going to happen and pictorial sequences. In contrast, others prefer to not to know in advance as it leads to obsessive worrying. Some people like time to receive, absorb and discuss information prior to a procedure, while others prefer sedation as soon as possible.

Findings and specific recommendations for emergency departments

In recognition that emergency departments can be especially stressful for children with ASD and their families, a number of hospitals, most particularly in the United States, have attempted to make emergency rooms more accommodating for children with ASD. For example, in 2014, an initiative was undertaken by Capital Health Medical Centre, in Hopewell, New Jersey, to make its paediatric emergency department more ‘autism-friendly’. Strategies that have been implemented included the availability of electronic hand held devices to communicate with children, the availability of sensory toys and textured stimuli for children to play with while they were waiting and the reduction of florescent lighting. See: http://www.capitalhealth.org/news/2014%20News%20Articles/Autism%20 Friendly%20ER%20Opening

A pilot program has also been introduced at the Nemours Children’s Hospital in Orlando, Florida. Parents are asked if their child has autism and if so, are offered access to a separate quiet room with stress relieving equipment, such as sensory toys and headphones available for use by the child with ASD while they wait. When possible, the child can also receive assessment and interventions in this designated room, with staff trained to expedite and modify the assessment and treatment process and to reduce the use of unnecessary monitors. See: http://theautismfamily.com/tag/nemours-childrens-hospital/ Anecdotal reports support these approaches and a more formal evaluation is apparently underway.

In the report from the enquiry into services for people with ASD undertaken by the Parliament of Victoria (2017), a similar recommendation was made.   Specifically, that ‘The Victorian Government ensure all new and existing public hospitals and healthcare facilities have provision for dedicated quiet spaces for people with ASD in emergency departments and other inpatient and outpatient areas'.

Jeanette Perkins (2016) has provided a practical online article entitled 10 Things ER Staffers Should Know About Autism. Jeanette has ASD and a mental illness and she reports that her experience of attending an emergency department has always been traumatic, invalidating and unhelpful leading to her avoidance of treatment. See: https://themighty.com/2016/07/things-er-staffers-should-know-about-autism/

Findings and recommendations for outpatient, community and dental health settings

Outside of the acute care setting, office based health care delivery such as a visit to a general practitioner, specialist physician or allied health professional has its own challenges for children with ASD. For example, in these settings there may be a limited time allocated to the appointment, as well as limited personnel and resources (Bultas, McMillin, & Zand, 2016). In a study of 54 health care providers and 59 parents, Bultas et al. examined barriers and evaluated a 'quick tips profile card' designed to facilitate improved health care delivery in office-based health care settings. Child behaviours, communication difficulties and child fears were reported by the health care providers as the greatest barriers to providing care. For parents, the greatest barriers were child behaviour, sensory issues and a perception of disconnect with the health care provider. Both health care providers and parents provided a favourable response to the profile card.

There has been some work on the impact and management of anxiety in the provision of dental health services to people with ASD. Dental care presents particular difficulties for children with ASD due to their sensory sensitivities and fear of the unfamiliar often leading to high anxiety and uncooperative behaviour (Elmore, Bruhn, & Bobzien, 2016). Although parents emphasize that each child's oral care should be individualized based on parents' input about the unique characteristics and needs of their child (Lewis, Vigo, Novak, & Klein, 2015), dentists report a lack of knowledge in how to deal with individuals with ASD (Weil & Inglehart, 2010) and in many cases, dental work can only be undertaken under a general anaesthetic (Isong et al., 2014).

According to Nelson, Sheller, Friedman and Bernier (2015), outcomes can be enhanced though communicating with parents to determine child sensitivities and interested and preparing the child before the appointment with stories and videos of children receiving dental care. They also suggest that the environment is modified to minimize stressors and that treatment is undertaken in a series of small sequential steps.

In a review of available interventions to reduce dental anxiety in children with ASD, and to determine which strategies may be best suited for implementation, Elmore et al. (2016) described a range of picture exchange communication cards, video technologies and mobile applications. While each of these has evidence to support its use to assisting a child with ASD to access dental care, the authors emphasize that the heterogeneous nature of this population means that there is a need for an individualized approached whereby the practitioner collaborates with caregivers in order to minimize the child's stress and enhance their comfort and co-operation.

On the basis that many children with ASD have a strong preference for visual stimuli, Isong et al. (2014) evaluated the impact of electronic screen media in reducing anxiety and uncooperative behaviours in children with ASD and a known history of dental fear who attended the Boston (USA) Children's Hospital dental clinic. In a controlled randomized trial, levels of anxiety and behaviour were assessed at each of two preventive dental visits six months apart. There was no difference between visits for children who received usual care or who watched a DVD recording of a typically developing child undergoing a dental visit (video peer modelling). In contrast, the mean scores reduced significantly (P=.03) in those children who watched a favourite movie during the dental visit using sunglass-style video goggles) and those who viewed both the peer modelling video and viewed their favourite movie with video goggles. Although there was no significant difference between groups over time, this may be the result of the small sample size and it nonetheless appeared that electronic screen media technologies may be useful tools for reducing fear and uncooperative behaviours among children with ASD undergoing dental visits. The authors suggest relevance to providers of health care to children with ASD in other medical settings.

As recommended by the Victorian Parliament (2017), there is a need to develop education and training options to dental clinicians in understanding ASD and the way in which ASD presents in their patients. There is also a need for ongoing research and evaluation of strategies in the provision of dental health services to people with ASD.

Enhancing communication

Communication difficulties are a core feature of ASD, although the nature and extent, as well as the range of communication strategies used, differs across the population. For example, in Kopecky et al.'s (2013) study, only 23% of patients with ASD were reported to express their needs verbally, with 38% using sign language and gestures and 31% using electronic devices or picture exchange communication tools (PECS). Similarly, these communication devices, as well as 'first/then' boards and social stories were used by 57% of this sample in order to understand new information or instructions. Importantly, in the Amaze survey (Stagles, 2016), 66.3% of the participants felt that the nurses had not supported the child's communication needs while they were in hospital.

Difficulties in communication may result in the child with ASD not understanding procedures or expectations, thereby further elevating their anxiety (Muskat et al., 2015). Communication deficits may also hinder information flow between the child and the healthcare professionals, impacting on assessment and treatment. For instance, a child may be unable to effectively communicate their physical symptoms, their emotional state, or the nature, location or the level of their pain to hospital staff (Muskat et al., 2015). In nonverbal patients, in particular, pain may be communicated through maladaptive behaviour. In Kopecky et al.'s sample, for example, it was reported that only 19% of the children expressed pain via spoken language, with 32% doing so via crying or screaming and 27% thought to exhibit their pain via self-injury or aggression.

In addition to communication difficulties, it is important to note that the measurement of pain may also be impeded through the different pain thresholds evident in people with ASD and leading to the possibility that standard measures maybe unreliable (Allely, 2013; Benini et al., 2004; Van der Putten & Vlaskamp, 2011). In a systematic review of publications on pain in children with ASD, Allely (2013) confirmed different patterns of pain experience and expression of discomfort in children with ASD compared with typically developing children. The pain threshold issue was emphasised by parents in the Amaze survey (Stagles, 2016) and is particularly problematic when, for example, a child has little or no obvious pain reaction to a compound fracture of an arm. As noted by Allely, the absence of a typical expression of pain cannot be assumed to mean that the child is not in pain, thereby again highlighting the critical need for consultation with parents /caregivers.

Effective communication between a health care provider and patient is essential to providing quality care. Good communication can help to relieve anxiety and is critical for assessment of symptoms and pain. Recognizing that children with ASD have a range of communication difficulties, it is important that strategies are developed to maximize communication between the child and the health care provider. The parents are usually the best source of information and must be consulted as to what communication strategies work best for their child. For example the use of a well-designed cartoon type picture sequence of a medic al procedure might be helpful for some children with that level of capacity of symbolic representation but will not help of even stress a child who is more delayed and might better respond to photographs. For children with receptive language ability, a straight forward approach to communication is recommended (Scarpinato et al., 2010). However, verbal instructions need to be concrete, logical in sequence (e.g., first A..., then B...) and presented by one person at a time (Johnson, Lashley, Stonek, & Bonjour, 2012). For children who communicate non-verbally, communication aides are recommended to facilitate a dialogue, such as a communication board (Muskat et al., 2015; Scarpinato et al., 2010), cards with content specific to the health care setting (Scarpinato et al., 2010) or the use of electronic hand held devices with special auditory and visual icons (Luthra, 2016). The likelihood that children will have a concrete and literal understanding of information given can also create stress for example if there is a change in sequence of a procedure, or a detail such as the type of X Ray machine used in the picture script is different from the one in reality.

The importance of recognizing heterogeneity and individualizing approaches to communication is demonstrated with respect to the difficulties that some individuals with ASD have with being told that they need to wait. Although in Kopecky et al. (2013) it was reported that 8% of patients with ASD were not able to understand the passage of time, 30% could do so using a scheduled board, a clock (20%) or a timer (17%), or by counting aloud (17%). These findings show the importance of obtaining information about the individual and their strengths so that approaches to assist them can be individually tailored. As emphasised by Kopecky et al., the development, in consultation with the parents, of a sound inpatient care plan rests on an individualized assessment of communication strategies, behavioural responses, and sensory sensitivities.

The literature identifies a range of devices and strategies that may assist the individual with ASD to communicate and to better understand procedures. In addition to communication devices, such as communication boards, these include communication apps, resource kits with storybooks, picture schedules and social scripts, and the use of virtual reality.

Communication Apps

A number of communication devices and strategies are now available to assist some people on the autism spectrum if they have the cognitive capacity and experience to use them. For example, an online article by Rachel Kassenbrock describes an app that provides a voice for some individuals, unable to speak during an emergency (see: https://themighty.com/2015/07/this-new-app-provides-a-voice-for-anyone-unable-to-speak-during-an-emergency1/) with materials to upload available at http://themighty.com/wp-content/uploads/2015/07/EC-App1.png

The “Emergency Chat” app was developed by Jeroen De Busser, a computer science student with ASD at the University of Antwerp in Belgium that makes it possible for some individuals to communicate quickly when they are unable to speak and either require assistance or need to communicate to others so that they do not inadvertently contribute to a problem. The app allows these individuals to access a pre-programmed message on their phones during an emergency and hand it to someone who can then use it for two way communication using a basic chat interface. The user can then explain specifically and quickly how others can help. Example display options include:

“Aspie meltdown”

e.g., *I gave you my phone because I cannot use or process speech right now but I am still capable of text communication. My hearing and tactile senses are extremely sensitive in this state, so please refrain from touching me. Please keep calm, and proceed to the next screen that has a simple chat function through which we can communicate.*

“Asthma attack”

e.g., *I am having difficulty breathing due to Asthma and I need your help. I am prescribed an inhaler. If I do not have it with me, please call and ambulance to take me to Emergency immediately. Please help me to calm down and slow my breathing so I can inhale. I need one or two puffs spaced about a minute apart. Press continue to give me a voice.*

Resource Kits

Several authors have recommended the use of a resource or ‘Toolkit’ that includes materials to assist the patient with ASD, and sometimes to also assist staff. Some of these are particularly relevant to pre-admission, while others emphasise the perioperative period and preparation for a particular procedure. For example, MacKenzie et al. (2013) described a resource kit that included a child friendly storybook that enabled the child to gain information about their forthcoming procedure so that they may prepare. Scully (2015) described a perioperative Toolkit that included a social script explaining the steps with accurate pictures, to be viewed at home to prepare for expectation of the day of the surgery.

A coping kit including communication cards, a social script about going to hospital, paper and pencils, toys and self-calming devices such as a squidgy ball was developed by Drake, Johnson, Stoneck, Martinez and Massey (2012) to support children with ASD in acute care settings. In a detailed evaluation involving 24 nurses, the majority (70.8%) reported their view that the kit helped their patients to be less anxious and to cope with procedures.

Kopecky et al (2013) developed a toolkit for hospital admission that includes photographs of the different areas of the hospital, reusable PECs, a picture board, headphones, earplugs, weighted blankets and maps of the hospital. This toolkit also includes copies of a pain scale (the Face, Legs, Activity, Cry, Consolability (FLACC; Voepel-Lewis, Zanotti, Dammeyer & Merkel, 2010) and the Non-communicating Children’s Pain Checklist (Breau & Burkitt, 2009).

The internet is also the source of a number of interesting resources, with the potential to assist people with ASD. For example, the USA advocacy organization, Autism Speaks, has developed a number of tool kits to assist with the preparation of children with ASD for medical procedures. See: www.autismspeaks.org

Many of the available tool kits include visually presented sequences demonstrating the anticipated steps involved in the forthcoming processes and procedures. Where the toolkits have been evaluated, the findings are largely positive, although there remains a need for greater evaluation of which of the range of components that may be included are the most effective and with whom. The effective use of any toolkit will depend on its match with the individual differences, such as the comprehension level of the child.

Picture schedules and social scripts

Children with ASD commonly experience cognitive and social difficulties in discerning, understanding and predicting novel situations and sequences, potentially leading to high anxiety. In recognition of these difficulties, together with their often compromised communication skills, picture or visual schedules (sometime referred to as social scripts or social stories, particularly when the content includes interpersonal interactions) are a recommended strategy to prepare individuals with ASD for new experiences. Picture schedules are a series of images that show the nature and sequence of steps and the apparatus/devices involved in a particular activity or process. Social scripts or stories are written to break down a complicated abstract procedure, such as having an x-ray into a sequence of smaller steps. The scripts also provide short explanations of the reasons for procedures, what might happen, as well as what is expected from the patient. Initially developed by Carol Gray, (see Gray, 2000) social stories have been promoted as a strategy to prepare children with ASD for novel interpersonal encounters, including a visit to a medical practitioner (Mills, 2012). Social stories may be supported visually by drawings or photographs, and are now widely available on the web, via electronic hand held device and mobile phone applications (apps). It is important that picture schedules and social scripts are available in both hard copy and electronically so that patients and their families can access prior to their hospital visit.

There is some research on effects of these interventions on decreasing anxiety in children with ASD undergoing medical procedures. For example, in a pilot study, Johnson et al. (2014) evaluated social scripts delivered via electronic hand held device to prepare 32 children with ASD for a medical imaging procedure. In comparison to a control group who did not have access to the intervention, lower state anxiety was evident in both parents and children and fewer challenging behaviours were demonstrated in children who had access to the intervention.

On the basis of an identified lack of evaluations of the use of picture schedules in medical settings, Chebuhar et al. (2013) developed a range of picture schedules involving actors participating in medical procedures, such as the measurement of weight, height and blood pressure, giving an injection, or inserting an intravenous (IV) line. In a pilot evaluation, simple rewards (such as stickers) were given to children as they participated in each component of the sequence. According to 87.5% of staff, the schedules reduced anxious behaviours and overall distress in the children. According to 77.8% of parents /caregivers, the picture schedules reduced anxious behaviours and made the overall experience more tolerable for their child.

Thompson et al. (2014) evaluated a visual chart with mixed results. The chart did appear to assist the children to appreciate what would happen next and the flow of day. However, many of the participants found it overwhelming and suggestions were received from parents that it be adapted so show only the major steps – i.e., fewer pictures, with a focus on those related to key topic of anaesthesia. These findings once again highlight the importance of individualizing interventions. It may be helpful for families and children to devise their own picture chart from a selection of pictures according to preferences.

Use of virtual reality

Exposure therapy is highly efficacious in the treatment of anxiety and the exposure component can be delivered either directly (in vivo), or via visualization and imagination (Gorini & Riva, 2008). It can also be delivered via virtual reality technology, enabling the individual to be exposed to anxiety-prompting stimuli in a way that is closer to reality than can be achieved through imagination (Gorini et al., 2008; Gebara, de Barros-Neto, Gertsenchtein, & Lotufo-Neto, 2016). The application of virtual reality technology has been used to assist people to manage their anxiety and although some studies fail to meet methodological criteria (Page & Coxon, 2016), overall the results are increasingly promising (Opris et al., 2012; Morina, Ijntema, Meyerbröker, & Emmelkamp, 2015).

Virtual reality technology has recently been trialled to assist people with ASD to manage their anxiety. In an Australian study, Carey, Constable, Sprick, & Parker (2016) evaluated the impact of access to an online interactive walkthrough of the environment and the processes involved in an optometry examination prior to their appointment on reported levels of anxiety in children and adolescents with a diagnosis of ASD. In a controlled study with 34 children with ASD aged 8-18 years (17 randomly allocated to each of the intervention and control groups), those who had access to the interactive virtual tour before the appointment reported significantly lower levels of anxiety at arrival and during the visit according to a visual method of reporting than those who did not (p= 0.01). Although the results are preliminary, the authors suggest that the use of a short 3D virtual video of an unfamiliar health care setting may reduce anxiety levels of children with ASD, enabling more reliable assessments and improved services.

While there are expensive options, immersive interactive 3D experience can be achieved through equipment that it not extraordinarily expensive. In this study, Go Pro cameras @ Au$550 each were used, although they can take many hours to process, produce a large file, require a powerful computer and an expert to process and upload the files. As an alternative, the researchers recommend a 360FLY camera @ Au$650, <15 minute to stitch together, requires little expertise and can be uploaded from the camera to a YouTube-like web page that can be accessed via a mobile phone. See: https://www.youtube.com/watch?v=DQdlMARA6ck&feature=youtu.be (2.35 minutes).

The critical role of health care staff

Despite findings from the Amaze survey that in most cases, hospitals in Australia supported the use of strategies which helped the young person during their visit (e.g., electronic devices or toys to distract the child, provision of preferred food and drinks, orally administered medications rather than via drip), this was not always the case, in particular, with regard to supporting the child's communication and sensory needs (Stagles, 2016). It thus appears that there are some significant gaps in understanding among some hospital staff of the impact of autism on the hospital experience, as well as in the uptake and application of proactive interventions to improve the patient experience and the quality of care.

Health care staff are critical to the provision of best care to children with ASD who present with health care needs. However, staff levels of comfort, self-competency and knowledge about ASD and its health care implications are variable. Davignon et al. (2014) reported from a survey of health care providers that training is often inadequate, most particularly in knowledge and skills for communicating with children with ASD and in behavioural strategies to improve interactions and manage escalating behaviours. The need for increased ASD training of emergency department staff was highlighted by Golnik, Ireland, & Borowsky (2009). According to Broder-Fingert, Ferrone, Giaque, and Connors (2014), paediatricians in the United States do not feel adequately trained. In a survey of 539 pediatricians and family doctors, respondents reported that their self-competency in providing care to individuals with ASD was significantly lower than was the case for those with other neurodevelopmental conditions (McGonigle et al., 2014a).

The challenges faced by health care staff in meeting the needs of individuals with ASD have been well acknowledged (Zwaigenbaum et al., 2016; McGonigle et al., 2014; Sakai et al., 2014). Particular concerns have been raised by health care practitioners, predominantly nurses, regarding the ineffective management of challenging behaviours of children with ASD in health care settings (Rhoades et al., 2007; Weil & Inglehart, 2010) and it is widely acknowledged that challenging behaviours can cause elevated stress in health care providers (Carbone et al., 2010; Scarpinato et al., 2010).

Clearly best quality care rests on ensuring that staff are adequately trained, both initially and through ongoing professional development opportunities, to respond to the unique presentation and the behavioural, communicative and sensory characteristics of ASD that may impact on health care delivery. According to Vaz (2010), an understanding of how ASD symptoms may present in stressful environments is an essential component of training and staff need supported through ongoing access to online information and resources.

In a survey of staff undertaken by Muskat et al. (2015), although there was variability in experience and perceived need for training, most staff expressed the desire for additional training. Importantly, there is some evidence that staff training has the potential to enhance outcomes for children with ASD. For example, Johnson et al. (2012) reported an increase in knowledge and a decrease in anxiety in staff who care for children with developmental disabilities and challenging behaviour following participation in a training program.

An important finding of the recent survey conducted by Amaze (Stagles, 2016) was that although most parents opted to inform the nurse of their child’s diagnosis, only 62.4% of nurses had heard of autism. Importantly, the majority of participants (60.6%) felt that the nurses did not know how having autism might impact on a hospital experience, 61.7% felt that the nurses did not try to support their child’s sensory needs while they were in hospital, and 46% reported that staff were not receptive to suggestions with regard to adapting care to meet the needs of someone on the autism spectrum.

Research by Johnson et al. (2014) further highlights a possible gap in staff knowledge. In this study, parents and nurses differed in the meaning attributed to the child’s challenging behaviour. Nurses attributed the behaviour to aggression and self-stimulation whereas parents believed it to be an expression of frustration, an attempt to self-calm and hyperactivity. While it is not possible to conclusively determine causality in these cases, because attributing the same behaviour to different causality could nonetheless result in different intervention responses, it is important that staff are fully informed regarding the range of possible etiological explanations.

There are several published works on capacity building in health care providers. Drawing on the literature, Johnson et al. (2012) designed a pilot staff training program in a paediatric hospital, emphasising the importance of family centred care approaches and individualized communication strategies in the prevention and management of challenging behaviours. A range of strategies were included in the training, such as consulting parents regarding triggers, how the child communicates and how they express pain; emphasising that only one person talk at a time; practice at explaining what they are about to do; practice in using posture and body language, tone of voice and choice of words to instil calm and security; and modifying aspects of the environment that the child finds challenging. The program was comprised of 1 hour on line and 1 hour face to face training and included a series of videos of staff modelling strategies for preventing or dealing with challenging behaviours and the opportunity to practice communication methods. Participants reported enhanced knowledge and decreased anxiety about working with children with ASD who may display challenging behaviours.

Jolly (2015) provides a valuable resource to prepare and inform nurses in the provision of inpatient treatment of a child with ASD. Nicholas et al. (2016) describes the inclusion of ASD content in initial training programs and in professional development for existing staff that includes “simulated care scenarios” and video resources. The importance of cultural competence in those who are working with children with special health care needs has also been raised (e.g., Kerfeld, Hoffman, Ciol, & Kartin, 2011) and is relevant to staff training.

In addition to the possibility that challenging behaviour may arise from difficulties coping with the hospital environment, acute agitation and aggression can lead the person with ASD to present to a hospital emergency department in a state of crisis (Bradley & Lofchy, 2005). In many such cases, the emergency department experience has not been positive. For example, there is case study evidence suggesting that serious negative outcomes may result from misdiagnosis of individuals with ASD (Smith, Gravelin, & Smith, 2012). Misdiagnosis may arise at least partly from the absence of staff training in differentiating core symptoms of ASD from other conditions, with a possible outcome being the delivery of an inappropriate intervention (McGonigle et al., 2014a). McGonigle et al. present a model to assist staff to undertake a crisis evaluation and to adapt the emergency department procedures for an individual with ASD in order that their anxiety is managed in line with a least restrictive philosophy and enabling the provision of treatment. In addition, Nicholas et al. (2016) describe the development of a toolkit for staff that includes strategies for the care of agitated patients and in particular, interventions for the de-escalation of aggressive behaviour.

As a first step to providing staff education, it is important to assess the knowledge, competency and confidence of health care providers, as well as the challenges they have encountered in providing health care to someone with ASD. There are a number of existing measures available to determine knowledge of ASD in health care professionals; however, these predominately relate to the presentation of ASD in children and the impact of ASD on child development (e.g., Bakare, Ebigbo, Agomoh, & Menkiti, 2008; Imran et al., 2011; Schwartz & Drager, 2008). There remains a need for the development of staff questionnaires that focus on training needs and for an Australian study to determine current training needs of staff.

Summary and recommendations

It is widely suggested from the existing literature that the challenges children with ASD experience in hospital and other healthcare environments may pose a significant barrier to the provision of optimal care. Given the high rates of hospital presentations in this group, the importance of ongoing evaluation of strategies to improve the experience of children with ASD in receiving health care is apparent.

The empirical, clinical and policy literature highlights several recommendations that show promise for improving the hospital and healthcare experience of children with ASD and their families. Key recommendations include:

1. Adopting a collaborative approach to care through the involvement of the parent/caregivers in patient planning.

2. The development of individually-tailored patient care plans involving pre-admission planning and assessment of the child’s needs, including communication, social, pragmatic and safety concerns.

3. Using environmental modifications to address anxiety, sensory difficulties and challenging behaviours.

4. Enhancing communication with patients with ASD through clear verbal and/or nonverbal and visual strategies.

5. Training and building staff capacity in relation to self-competency, knowledge and comfort in the presentation of ASD and its impact on healthcare delivery.

Recognition of need for service user and service provider informed approaches

There is now widespread recognition of the challenges faced by children with autism who present to a health care facility, and particularly a hospital, for medical assessment, medical and surgical treatment and nursing care. There is also evidence that specifically tailored patient care-plans show promise for improving the experience of hospital care by these children with ASD and their families (Broder-Fingert et al., 2016). Hospitals are now seeking empirically-informed programmes and care-plans that are tailored to the specific needs of individuals with autism and are informed by child and care-giver reports of individual needs (Kopecky et al., 2013).

The Amaze survey (Stagles, 2016) confirms that the issues faced by children with ASD and their families in Australia are similar to those reported overseas. There remains a need for a deeper understanding of the needs of children with ASD in hospital settings, and for increased knowledge on the implementation of environmental modifications and clinical measures to create more autism-friendly hospital environments in Australia. It is important that such is knowledge is informed by both service consumers and service providers. In addition to our review of the literature, the studies that follow contribute to what is known through report of data provided from a survey of Cabrini staff and from individuals who participated in an autism-focussed audit of the Cabrini hospital - Malvern.

CHAPTER 3:

STUDY 1 - CONSUMER INTERVIEWS

Aim

The aim of this study was to explore the hospital experiences from the perspective of children with autism, and parents of children with autism who are currently or have previously attended Cabrini for medical care during the past 3 years.

Method

A short semi-structured interview schedule was designed for administration to a small sample of retrospective or current consumers of Cabrini health services comprised of children who have autism and their families. Participants were given the option of a phone interview or a face-to-face interview at a mutually convenient location (Deakin University or Cabrini). The consent procedure included permission for taping of the interviews to enable accurate transcription.

Invitations to participate were made available to family/caregivers and children with autism in the following ways:

1. Retrospective patients

a) Flyers/ an invitation to participate was sent to families of paediatric patients known to be on the autism spectrum, who have attended Cabrini for treatment during the last 3 years. This was facilitated by Cabrini nursing staff.

b) An information flyer was sent to Paediatricians rooms for distribution to patients known to have previous experiences in the paediatric ward during the last 3 years.

c) A recruitment advertisement was placed on the Amaze website. The Amaze website has a section dedicated to recruitment that lists current projects buy outlining research title; name of researchers; study aim/ background; who is suitable to participate; what is involved for participants; contact details and research end date.

In each case, those families interested in participating were asked to contact the study Research Fellow for further information and determination of eligibility.

2. Current in-patients

Study flyers with an invitation letter were made available to families of all paediatric patients during admission to the Children's Centre at Cabrini. Flyers were also distributed to families of paediatric patients who met the eligibility criteria. A child's name and their ASD diagnosis is documented on the ward handover sheet, meaning they are able to be identified to receive the study flyer/invitation to participate. The flyer directed families who may be interested in participating in the study to contact the project Research Fellow directly for further information.

3. Up-coming admissions

a) During the designated study period (27/2/17 to 30/6/17), flyers with an invitation to participate were provided to families during pre-admission by the Paediatric Admission Clinic staff.

b) During the study period, study flyers were also sent to Cabrini paediatricians rooms for access by prospective patient families.

In addition to consent for their own participation, parents or guardians were asked to provide consent on behalf of their child. This was deemed appropriate given their knowledge of their child's characteristics, capacity and likely willingness to participate. In conjunction with parental consent, the Research Fellow was required to discuss the research with the child (what the study is about, what will happen and that they can say no to participation at any time) and seek their assent to participate. The Research Fellow was trained to undertake these discussions in a manner that was developmentally appropriate to the age and other characteristics of the child and that allowed sufficient time for questions and further explanations, as well as the opportunity for the child to express and discuss their willingness or unwillingness to participate. This methodology is in line with the reference in the National Guidelines on the benefits of engaging young children with limited cognitive capacity in discussions at their level of understanding, although the child's "consent" is not required [4.2]. Throughout the study, the Research Fellow was to assess the child's assent through verbal and behavioural signs, and to discontinue if there were any signs of reluctance, fatigue or irritability.

We endeavoured to recruit a sample size of up to 20 families of children with autism who have attended Cabrini during the 3-year period (late 2014 to early 2017).

Results

Despite recruitment advertisements, the distribution of numerous recruitment flyers and efforts from the Cabrini researchers to recruit families and children to the study, we were unable to recruit any families of children with autism who had been patients at Cabrini during the past 3 years. One family indicated interest in participation, but despite follow-up, did not return the consent forms and proceed to interview.

Ethical constraints, in particular patient confidentiality and restricted access to health records, limited recruitment strategies. It is possible that some potential participants did not respond due to having already completed the online Amaze survey on hospital experiences, conducted in April 2016. It is also possible that caregivers of children with autism, and in particular those who have co-occurring medical conditions and who had currently or recently been admitted to hospital, may simply be too busy or otherwise not able to participate in a face to face interview.

It became apparent during recruitment efforts that there is currently not possible to recall ‘flagged’ information on a selective group of patients (i.e., patients 'flagged' with ASD). The inclusion of a 'visual flagging' mechanism on the Patient Administration System (PAS) is recommended.

CHAPTER 4:

STUDY 2 - STAFF SURVEY

Aim

The aim of this study was to ascertain the experiences, views and training needs of current Cabrini staff. This was regarding children with autism presenting to Cabrini hospital for health care.

Method

Cabrini staff (nurses, doctors, allied health, administrative and support [ward assistants and personal care assistants] domestic and food delivery services) who interact with children across paediatric settings were invited via email to participate in an online anonymous survey. The survey aimed to determine their understanding of the needs and challenges faced by children with autism and their families in hospital, their experience and confidence in meeting the needs of children with autism and their perceived needs for additional training in this area. The survey was delivered through the Cabrini Audit and Survey Program (CASPro) and was comprised of 12 questions, inclusive of Likert-type response options and open-ended formats. The survey opened on 30th March 2017 and closed on 30th May 2017. Quantitative data are presented as figures, while responses to open ended questions are grouped according to key themes. Direct quotes are used wherever possible to demonstrate themes, bringing richness to understanding. Content was examined according to three key areas: difficulties experienced by children and families, pre-admission requirements and suggestions for improvement. Material provided in a final section inviting further comments was shifted to other areas as relevant.

Results

Participants

A link to the survey was sent to 302 staff, comprised of 208 nurses from emergency, theatre and the day procedure centre, 24 paediatric ward nurses, 8 paediatricians, 2 dieticians, 54 menu monitors/ food delivery staff, 3 domestic staff, 3 administrative staff. A total of 31 staff participated in the survey (10.3 % response rate). Specifically, responses were received from 21 nurses, 3 administrative staff, 2 dieticians, 2 domestic staff, 2 food delivery staff and 1 paediatrician. The reported length of time staff had worked with children in a healthcare setting varied from less than 5 years (n=6); 6-10 years (n=9); 11-15 years (n=6); 16-20 years (n=4), with 6 participants having worked in this setting for greater than 20 years.

Experience in ASD

Nearly half of the respondents (n=15; 48.3%) reported having at least some experience with children with ASD in non-medical settings (see Figure 1).

Figure 1: Level of experience with children with ASD in non-medical settings

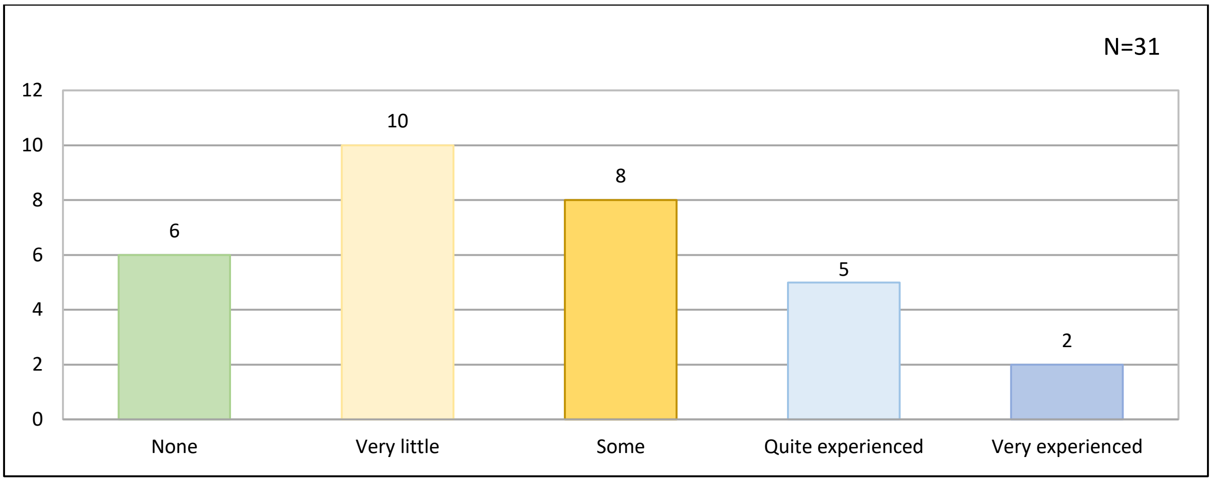


Figure 2: Level of experience with children with ASD in medical settings

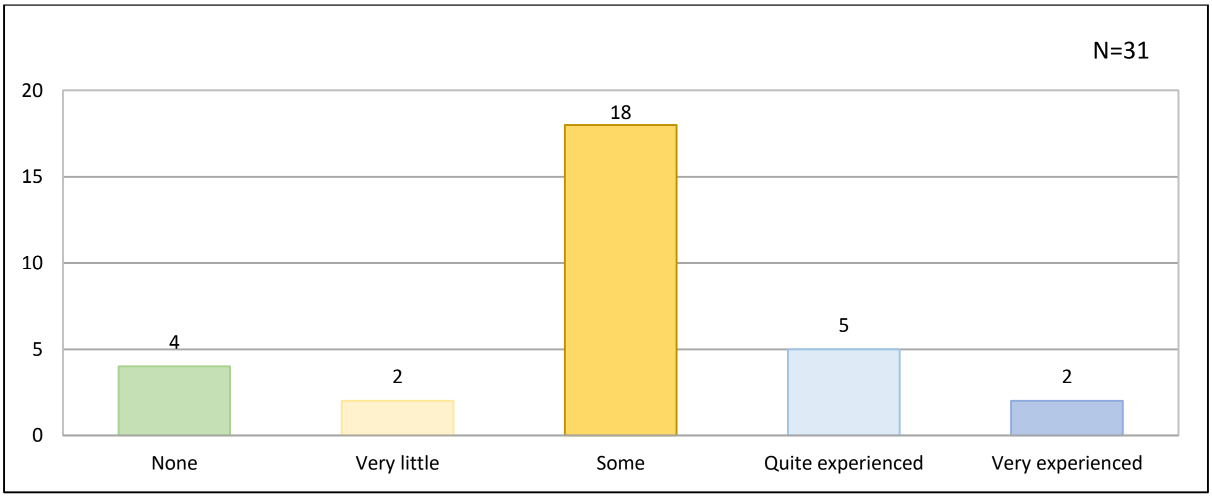
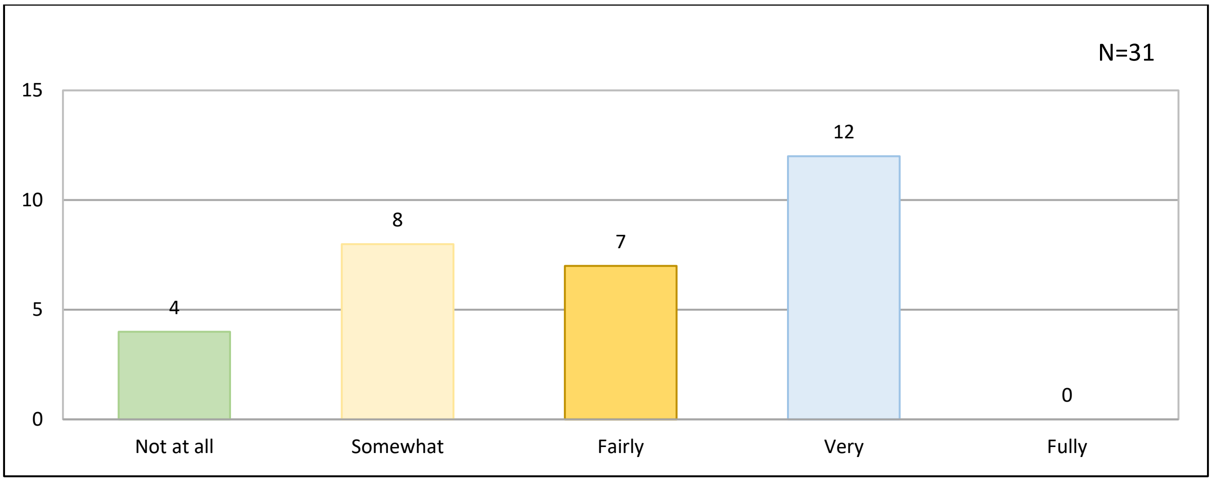


Figure 2 shows that most respondents (n=25; 80.6%) had at least some experience with children with ASD in a hospital setting, with 22.5% rating themselves as quite or very experienced.

Confidence in ASD

When asked how confident in their current role at Cabrini they felt in providing health care/service to childen with ASD, while none of the respondents were fully confident, 39% (n=12) reported that they were very confident. As seen in Figure 3 below, however, 48.4% were only 'fairly' confident or 'somewhat' confident and 12.9% were 'not at all' confident. These findings suggest that there may be a need for staff training in ASD.

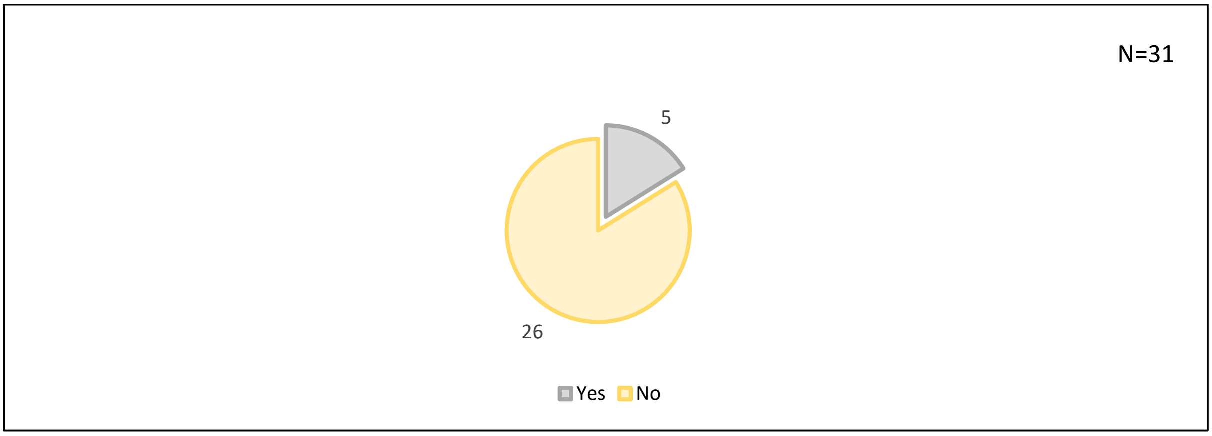
Figure 3: In current role at Cabrini, level of confidence in providing care/service for a child with ASD



Training in ASD

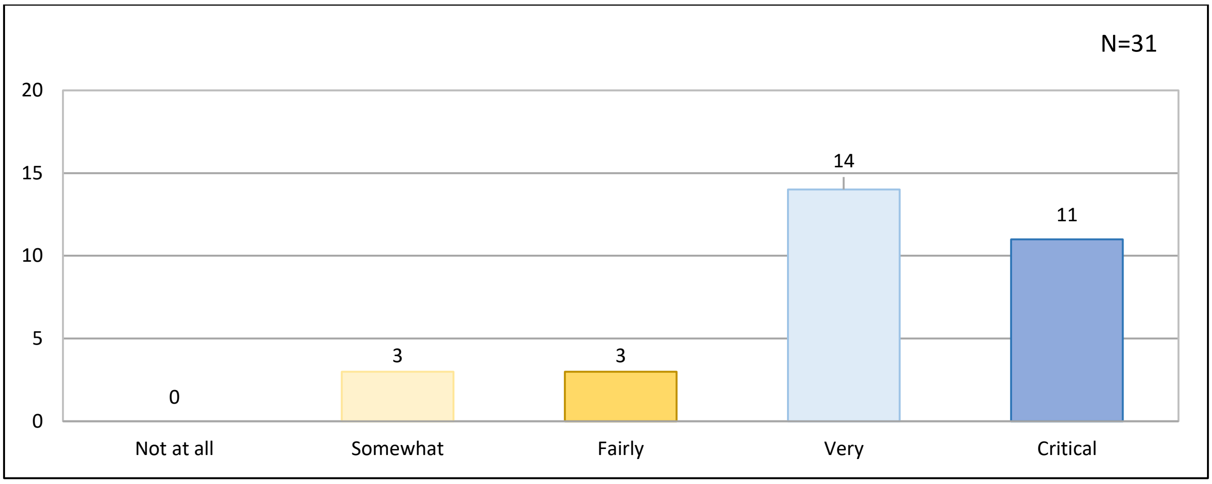
As demonstrated in Figure 4, the majority of respondents (n=26; 84%) reported that they had not undertaken any training relating to working with children with ASD. Of those 5 (16%) who had received some training, it included ABA therapy, a short course, conferences highlighting ASD, and a paediatric fellowship.

Figure 4: Extent of any training relating to children with ASD



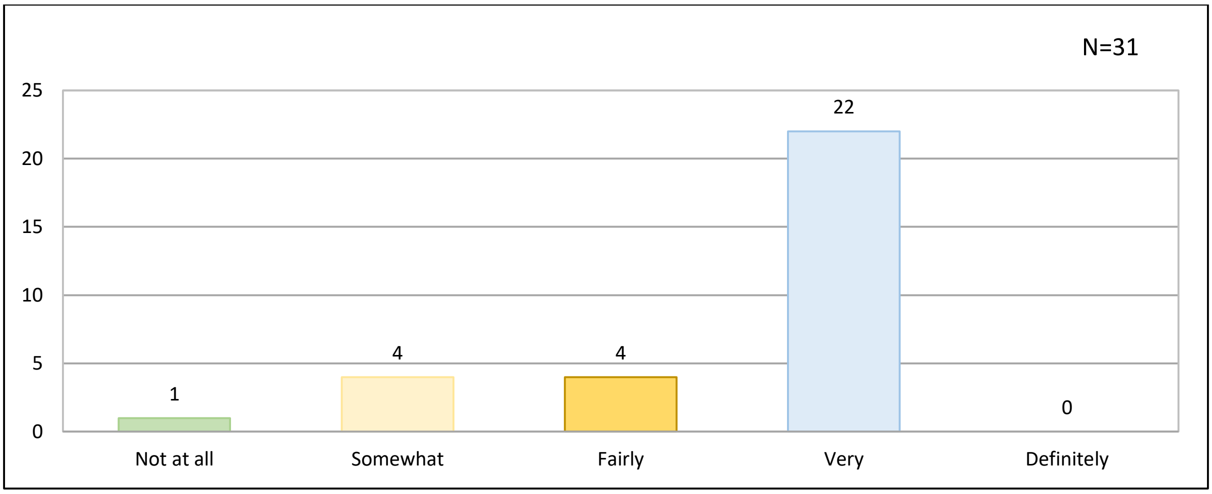
The majority of respondents thought it important that staff receive training in ASD (see Figure 5). Specifically, 45.2% thought it very important and 35.5% believed it to be critical. No one reported that it was not at all important for staff to receive training in autism.

Figure 5: Rating of importance that hospital staff receive training in ASD



When asked how likely it would be that they would attend training about ASD, 71% reported that it was very likely (Figure 6). The individual who was not likely to attend training reported that given don't have any contact with children with ASD, they would prefer the opportunity was afforded to staff who do.

Figure 6: How likely is it that you would attend training about ASD?



Difficulties experienced by children with autism and their families attending hospital

When asked to describe the most difficult things about a hospital visit for children with autism and their families, most of the comments provided by respondents related to the disruption of the child's routine, long wait times, the unfamiliarity of the people and surroundings and the challenging sensory aspects of the environment. For example:

> *"New people… new experiences."*
>
> *"…changing routines… changing staff….different people assessing and monitoring."*
>
> *"....the fear of other patients, nurses and drs, when the child wakes up from surgery and the parent is not next to them as I have experienced....., they tend to scream out alot."*
>
> *"The simplest tasks can require hours of preparation and encouragement to undertake....When they move into an unfamiliar environment (like hospital), this creates another shift in thinking and those tasks become more challenging to undertake."*

Comments highlighting the **challenging sensory aspects** of the environment included:

> *"Hospitals are generally very busy, which for a lot of children with autism, can disrupt and upset them. They can become agitated and quite vocal in such high stress scenarios…."*
>
> *"Loud, bright and busy corridors." "....different food."*
>
> *"....people touching them, noises, lights, pain, bandages, - almost everything."*
>
> *"Sensory processing issues - bright lights, unfamiliar smells, noisy activity (particularly cleaners and call bells), fabric such as sheets and gowns can be coarse and scratchy, the feeling of bandages, tapes, gauze and wrist bands can be painful for those with sensory processing disorders."*
>
> *"The ED is often very noisy and chaotic. It is a very clinical space and there is often no opportunity to hide machines and equipment which can be scary or confronting for children, particularly those with ASD."*
>
> *"The recent uniform change has been very inhibiting to the care we provide to children with ASD. The bright red shirts are confronting and appear particularly intimidating, particularly to those children with sensory concerns. There have been more than one occasion where parents have asked staff to cover their shirts with a white patient gown before entering the room as their child is particularly sensitive to the colour and pattern."*

A number of specific comments regarding the Cabrini paediatric ward interactive play room were provided:

> *"A wonderful concept but there are many concerns that it is difficult for children to 'wind down' after playing in there. It also creates a very noisy environment in the ward and those children with ASD, while not physically being in the room, are affected by this over stimulation."*

> *"Too many people around - the play room in the new children's Ward doesn't have any quiet spaces to get away from noise, bright lights or people - what were they thinking??? The new ward is very noisy - rooms are either close to the nurse's desk or the playroom."*

Different sensory thresholds was also raised in the context of pain assessment and management.

> *"Different pain thresholds make it difficult for staff to get accurate information for diagnosis – under-feeling significant pain or over-feeling on minor pain is common."*

The **difficulty with transition** from one area to another was raised, and particularly the amount of time waiting around during the admission process.

> *"….transitions are extremely hard for many people with ASD and moving locations can be challenging. Starting in the day room, moving to holding bay, moving to theatre, waking up in recovery, moving back to the ward."*
>
> *"Long waiting times." "Having to wait to be admitted is challenging, despite the best efforts of staff to move quickly."*

Gaps in information and understanding was a key theme identified in responses. A lack of knowledge in both children and their parents about what to expect was emphasised.

> *"The 'unknown' – i.e. what it looks like, what to expect."*
>
> *"Knowledge gap of parents re: procedures and what to expect."*

While some children may attempt to find out about procedures prior to attending hospital, their internet based research and misunderstandings associated with it may actually increase their anxiety.

> *"Anxiety around the procedure itself - the child may not fully understand, or may have accessed YouTube to find out what will happen during the procedure. They may have accessed incorrect information from the internet. Literal understanding of things – e.g. needles don't feel like a mosquito bite because mosquitoes don't actually bite they suck. Saying the operation happens when you are 'asleep' can cause them to worry about any sleep, or that they might wake up, or feel something like when they are usually asleep."*

Pre-admission was highlighted as an area of difficulty in terms of knowledge and information flow.

> *"A real lack of knowledge by both staff and parents as to what to expect on admission."*
>
> *"As wonderful as pre admission is, we can never really know the child or parent till we physically see them, and them interacting with their parents/carers or siblings. Often at times parents are not as forth coming with information about their children and this has to be carefully elicited from them."*
>
> *"There is often not the opportunity to have lengthy conversations with patients and families. This can add to the frustration and anxiety of children being in a different environment making it challenging to for holistic communication."*

Pre-admission requirements

When specifically asked what should be included on a pre-admission checklist to assist hospital staff in providing the best care for a child with ASD, the respondents provided numerous specific suggestions for *"more information."*

Suggestions included the collection of general information such as:

> *"....medical history, age at diagnosis, severity of ASD or their functional level or level of interaction"*
>
> *"....the family situation and where they are placed in the family unit."*

It was recommended that children with ASD be provided with "*an identifier*" that signals to staff that they may have special needs, "*...so that staff can provide the right care and environment for the child*" and can "...*prepare before the child and their family arrives."*

The need for individual details on the child's ASD was emphasised as *"....all children are different*."

A dominant theme was the importance of **communication with parents**:

> *"Parents input is the most important aspect.''*
>
> *"Asking the parents what they are expecting from us."*
>
> *"What can we do to help you manage your child's condition while they are in hospital?"*

In particular, it was suggested that the pre-admission checklist includes a request for information on possible triggers for anxiety and challenging behaviours in the child, as well as suggested management strategies:

> *"The child's normal routine at home, preferred diet and how the child reacts to high stress/stimulation scenarios",* and *"the best way to avoid these triggers for the child."*
>
> *"What factors can contribute to worsening their condition in the hospital environment? What are the things most likely to cause upset or anxiety for this child? Are there any particular sensory issues to be aware of", such as "aversion to touch or loud noises?"*
>
> *"What calms them when they are stressed", what are their "coping mechanisms" and "...strategies for distraction and reassurance?"*
>
> *"What can we do to make the experience more comfortable for the family unit?"*

The need for information on how to communicate with the child was highlighted by several respondents:

> *"How best to approach and communicate with the child"*

> *“Do they relate to role playing, picture stories, etc.”*
>
> *“Are there any words to avoid ...things that should not be said in front of the child?”*

According to one respondent, the current pre-admission form is adequate. Specifically, the form is *“....quite inclusive of information relating to ASD or the like.”* In her view, however, it is the lack of consistency in the procedures that follow completion of the pre-admission form that cause difficulties.

> *“when the pre-admission nurse is not available; often these children and their families arrive without staff knowing anything about their history.”*
>
> *“To add to this, the parents have not received detailed information regarding their child’s stay to help prepare them adequately prior to admission.”*

There is a need for “*more consistency with the pre-admission clinic to ensure that all families receive a phone call pre-admission.”* If this was undertaken in a timely manner, it would enable the collection of more detailed information about the child, as well as the provision of pre-admission information and support, such as the option for “...*a pre-admission visit to the ward to help in preparing for the admission.”*

When children are admitted to the emergency department:

> *“...we don’t get the advantage of seeing a pre-admission form.”*
>
> *“We assess the child and obtain a verbal history from them and the family before paperwork is filled out. Communication of this information is very important and specific information relating to sensory, communicative and social issues with the child can often be miscommunicated or misunderstood when there is no formal structure or prior knowledge of ASD.”*

Enhancing the hospital experience

When asked what needs to be done to enhance the hospital experience for children with autism and their families and when further comments on providing an autism friendly paediatric setting at Cabrini were invited, the importance of seeking pre-admission information and working closely with families was again emphasised.

Suggestions regarding **pre-admission** included:

> *“Have a way to identify ASD. Gather as much information as possible prior to them arriving in hospital. Understanding ways to best approach the patient, prior to commencing tasks or asking questions.”*

> *"Pre-admission clinic phoning with more than 1 days notice to identify admissions and allow for planning" "....and allowing time to communicate effectively."*
>
> *"We need to decipher as much information gently, from the parent's pre admission, and on their arrival into the ward, so that we can truly make this a positive experience and a unique learning experience for all."*
>
> *"Surgeons/doctors must inform ward/nursing staff of any diagnosis and then pre admission to communicate with anaesthetist and theatre staff after having discussion with parents."*
>
> *"Trial runs for parents and patient to familiarise with surroundings."*
>
> *"Ward visits for children who are anxious could be arranged."*
>
> *"Have more available on-line for the families and child to view beforehand so they can be informed and knowledgeable before coming in."*
>
> *"A video tour of kids visiting the ward to see it (for example, like on Operation Ouch) and follow through the different places you go while here, some of the people you might meet, what kind of food there is, what you might have to wear to theatre, how you might get there, what the different sounds mean, what different words mean (e.g. paediatric, anaesthetist)."*
>
> *"Many ASD people are visual thinkers and learners and so having information easily accessible will be helpful e.g. website tour, written brochures given to surgeons rooms to give with the admission booklet, welcome to the ward/day room packs with information for the family."*

The importance of **working with families** was widely emphasised.

> *"Consultation with families, more communication between parents and staff, ask them what needs to be done to make the visit less disruptive."*
>
> *"Involve the parents at each step of the child's care - they are the experts in ASD and advocates for their child."*
>
> *"Ensuring that family are included in the plan of care and asked about behaviour triggers and best management strategy."*
>
> *"Respect the parent and their experience of their child - they have done this every day and are more likely to understand the triggers and clues in their behaviour."*
>
> *"Support for the parents - the time the child is in theatre is stressful for most parents but for people with a child with ASD it might be the only break they have had in ages. Listen to the unspoken communication the parents are giving - if their ASD child is present, they may not be able to say everything they need to as the child is finely tuned to verbal communication even though they may not be able to verbalise it themselves. E.g. Does mum need to speak to the staff under the guise of "popping out for a coffee"?*
>
> *"....areas for the parents to be involved in all care and stay."*

Respondents also talked about the anxiety experienced by some parents in supporting their child with autism and their worries that staff may misunderstand.

> *"Parents are anxious how their child will respond to care."*
>
> *"For the parents - preparing the child for admission is stressful. Trying to anticipate all the possible reactions he might have."*
>
> *"Worrying that staff will judge you, your child and your decisions because they are not familiar with what you have learned works for your child when they are stressed/distressed. Worry that the child might lash out in fear and hurt someone. Worry that a meltdown will be seen as a tantrum and staff won't know or understand the difference. Worrying about how they will react at home afterwards - knowing that if they can hold it together while they are there it will have to come out later - probably at home. Worry that people will think he is rude because he lacks the understanding of how to use tone in his voice to convey meaning. Worry that staff won't listen when I tell them he is getting close to overload - I can tell from his eyes and manner, but to most people they won't realise until it is too late."*

One respondent reminded us:

> *"Note that ASD has a strong genetic link, so there is potentially a sibling and/or parent/grandparent on the spectrum who may or may not also have a diagnosis. Be aware of how you communicate with the whole family - avoid saying things to other staff such as 'they were weird', etc."*

The critical nature of **individualized care** was also emphasised.

> *"All these children react differently to each other. There is no one solution for all children with ASD in respect to what the hospital can do but at least if we have a general idea it will help."*
>
> *"Remember, if you have met one person with autism, you have only met ONE person with autism. It is a spectrum and everyone will have a different profile, but there are many things in common which can help staff learn to understand."*
>
> *"....highly individual model of care /approach for each child and family."*

Many respondents raised the value of **promoting flexibility** in procedures, including minimizing waiting times and ensuring allocated to a single room where possible.

> *"Organising theatre lists so children can arrive with minimal waiting time will assist with concerns about fasting and the anxiety around clinical environments pre-op."*
>
> *"Flexibility...e.g. walking to OT not on a trolley coping with doing things in the way that suits the family not the hospital."*
>
> *"Change in policies / procedures to reflect potentially early discharge from PACU or the ward (if medically stable and Doctors are aware) where parents call from home if concerned."*

> *"In PACU (post anaesthesia care unit) ensure family are brought in as early as possible."*
>
> *"Facilitate fast transfer from ED to the ward wherever possible - minimise time in ED where all the senses are working overtime. Once we know they need to go to the ward, move them there."*
>
> *"Prioritise pharmacy and physio visits ahead of neurotypical children, to enable faster a discharge process."*
>
> *"I know it is impossible at times, but a single room seems to be so helpful for all."*
>
> *"Single rooms made available from time of admission (i.e. being able to hold them from the night before for known admissions)."*

The minimization of sensory overload was a common theme in suggestions provided by respondents. These included:

> *"....the use of appropriate colours."*
>
> *"The availability of quiet spaces in the day room and play room to combat sensory overload. Noisy activity – e.g. cleaners, food trolleys kept to a minimum in busy times. Moving food trolleys at 6.30 is a scary way for a child in an unfamiliar place to wake up. Vacuuming to be done at less busy times."*
>
> *"A quieter area for the post anaesthetic recovery phase. An isolated paediatric recovery that can be closed off from the main recovery area*."
>
> *"Ensure there is a safe quiet space available for children with autism and their families, in the event that the child becomes agitated/upset with the noise and/or stimulus within the hospital environment."*
>
> *".....the ED is a very busy working space. It is noisy and can be very chaotic. There are not enough quiet spaces that we can take patients and their families to during their stay to properly asses the child's condition. Ensuring a good rapport with staff is critical for communication of information. Often this is inhibited by the loud environment."*

Minimizing multiple care providers was also suggested.

> *"....assignment of a primary care nurse to limit interactions with multiple care providers as much as practicable."*

Many participants identified a need for **specialized equipment**, including communication devices.

> *"Visual pain scale charts - numbers are very specific and many children (even without ASD) will find it hard to choose a number for their pain. Grumpy - happy faces are much easier and also less likely to cause anxiety with a child who doesn't know which number to pick. Getting it "right" is very important to some HFA/Asperger's children and simply identifying a number for their pain can cause huge anxiety."*

> *“Visual schedule for each child, with a picture of each thing that has to happen in order.”*
>
> *“Sensory calming equipment - have a box with stress balls, wooden fiddle disks, fiddle toys, drawing and art supplies, etc.”*
>
> *“It would be great to have roof mounted TV’s in the paeds room and electronic hand held devices available for distraction for all children.”*

A number of specific comments and suggestions related to **communication** with a child with autism were provided:

> *“Don’t give too many choices for what to do. 2 choices are easier.”*
>
> *“Don’t focus on eye contact - as my son said to me once ‘It’s my ears that hear you not my eyes’. Many people with ASD find it easier to concentrate on what you are saying when they are NOT looking at you.”*
>
> *“Remember that behaviour is a form of communication- if the person is having trouble using verbal communication (even if they are usually verbal) then behaviour may be the only form of communication they have available to them. Don’t take it personally.”*
>
> *“Please don’t talk about the child in front of them if they are nonverbal. Just because they can’t talk to you, doesn’t mean they don’t hear and understand what you are saying, or even misunderstand and then get scared. Focus on what the child CAN do, small steps are sometimes needed to get compliance.”*

In addition to increasing the availability of *“specialist paediatric therapists”* a significant emphasis on the need for **staff training** was made by respondents.

> *“Education is very important and should be introduced across the organisation in all roles.”*
>
> *“Education specific to ASD in relation to varying staff roles should be mandatory.”*
>
> *“Every department has contact with children with ASD in some manner during their stay so it important that training is appropriate for the level of face-to-face contact to enhance patient and family experience.”*
>
> *“Having staff that are trained to care for these children in an environment where other staff are available to witness / experience this also.”*
>
> *“Educate staff (ED) on dealing with kids with ASD.”*
>
> *“As food delivery staff we do not know if we can enter the room to deliver or collect the food trays without disturbing the child’s space. Can we interact with the child easily should the need arise. Is it ok to knock if the child prefers to be in a dark room, etc.”*
>
> *“Having the skills to look after a child/teenager who is not coping and showing severe reactions due to fear/anxiety.”*
>
> *“I think it is so important for hospitals to invest in staff training for ASD. We are seeing many more children diagnosed at younger ages and it is become much more prevalent in hospitals. Even knowing the basics of ASD will assist us in caring for them during their stay.”*

Working toward the provision of an autism friendly hospital environment was considered to be:

"... a terrific initiative. I really hope there will be lots of education for staff around ASD and the various challenges it presents for the person, their family and those caring for them".

In addition to education, a need for ongoing support was identified.

> *"....good supervision/consultation process."*

Summary of findings

In sum, this survey of Cabrini hospital staff demonstrated an awareness in responding staff members regarding the difficulties experienced by children with autism and their families, when attending hospital.

The importance of individualized care and the acknowledgment of the critical role that family members can play in informing care was a key theme. This was particularly emphasised with respect to the pre-admission process, with respondents identifying a need for more information to be elicited from parents before their child arrives at the hospital. It was suggested that this information should then be disseminated to all staff who may be involved in the care of the child.

With regard to children with autism, respondents emphasised the need to minimize sensory overload, and also highlighted the difficulties which may arise in transferring the child from one area to another. Maximizing flexibility in the provision of care was also highlighted, and in particular, minimizing wait times and allocating the child to a single room. An emphasis was placed on the importance of tailoring care to each child in the context of their individual strengths and challenges and in recognition that anxiety or triggers for a ''meltdown'' differ in each child.

A dominant theme was the importance of staff training in areas such as communicating with, and caring for children with autism, and their families. A high level of interest in staff training was expressed, with none of the respondents reporting that they currently felt fully confident in caring for a child with autism.

CHAPTER 5:

STUDY 3 – AUDIT OF HOSPITAL ENVIRONMENT, PROCESSES AND PROCEDURES

Aim

The aim of this study was to gain an in depth understanding of the impact of the Cabrini - Malvern hospital environment, as well as the processes involved in attending the hospital for health care, from the perspective of young people with autism.

Method

Specifically, the method of this component was comprised of an in vivo walk-through of Cabrini Malvern and its Children's Centre by two or more volunteers with autism (pre-adolescent through to young adult; not required to have been a Cabrini patient), accompanied by the Research Fellow.

The rationale for the decision to recruit within this age range was based on the previous experience of the researchers in consulting young adults with autism who are able to provide informed consent and have some insight into their condition, as well as the ability to communicate the experience. Although we acknowledged that this may not be fully equivalent to the experience of younger children, or indeed that any one person's experiences will be the same as those of another, we were of the opinion that the feedback provided by an adolescent-young adult, would provide relevant, autism-specific feedback to inform the research.

Despite approaching several young people known to the researchers, it proved difficult to recruit volunteer adolescents with ASD for this activity. Individuals declined the invitation primarily on the basis of their anxiety about hospital settings. We were able to recruit three families. In two of these families, a parent (P1 and P2, both mothers) volunteered to participate on behalf of their child with autism who was not willing to participate. Specifically, one child aged 12 (C1) gave his mother the following reasons: a) I do not need to go to hospital, and b) I am not different to anybody else. The second child, aged 14 (C2), reported that it raised too much anxiety for her and she thinks she has enough hospital visits without coming for more. We were able to recruit one adolescent (C3 aged 15 years) who agreed to participate, accompanied by his mother (P3).

Each hospital walk-through commenced outside the hospital. The Research Fellow accompanied the participant(s) as they walked through the various areas in the hospital, as would be the case if they were attending for admission. The participant was asked to describe and comment on the experience to the researcher from the perspective of their child, or in the case of the young person with autism, from their own perspective. In addition to a walk-through of the hospital environment, the audit included an examination of processes and procedures experienced by children and their families attending the Cabrini Children's Centre. The Research Fellow recorded the participant responses verbatim. At the end of the audit, the participant mothers were asked to comment on the *Hospital Passport* created by The National Autistic Society in the United Kingdom to assist people with autism in hospital settings. The following two questions where posed: do you think this sort of thing might be helpful? What would you change or include to make it more helpful? All volunteer families were provided with a gift voucher to thank them for their participation and to cover their travel costs.

Results

Two of the researchers examined the data and selected the most representative quotes provided by the participants to identify autism specific needs and barriers in the hospital setting. Commencing with a description of the importance of understanding and minimizing hospital based triggers for anxiety, the findings are presented under the following broad headings:

- Issues with arrival, orientation and locating the children's ward
- Issues in the children's ward – dayroom, playroom, overnight rooms
- Disruption of routine and sensory challenges associated with a visit to the hospital
- Communication challenges
- Streamlining procedures and continuity of nursing care
- Collaboration with parents
- The Hospital Passport
- Summary followed by overall recommendations to address needs, reduce anxiety and minimize risk of challenging behaviours

As parent participants proceeded from arrival and progressed through the hospital, they commented on a large range of environmental and procedural features that would likely provoke anxiety in their child with autism, and may subsequently lead to a 'melt down' and associated challenging behaviours. The importance of understanding and minimizing hospital based triggers was highlighted by descriptions of potential outcomes from anxiety.

> *"Hospital visits are most difficult when C1's primal needs are not being met, like sleep, food, security, need for certainty and control. He gets more autistic and his ability to reason and think are reduced. It's much harder for him to regulate his own behaviour. His learnt coping mechanisms go and he just feels angry and tired." (P1)*
>
> *"Heightened anxiety can lead to heightened primitive behaviour, such as shouting, screaming and crying…… things like activating the fight and flight response, wanting to hide away or scrunch up and have a cuddle with mum". (P1)*
>
> *"....he senses a lump in his throat and he can't communicate. At these times, he says he just wants to withdraw from everything and needs to be in a dark and quiet place and not to communicate with anyone…. sensory overload can lead to a full-on panic attack, when this happens, we can't continue and it leaves us with no option other than to leave and go home immediately." (P3)*

Issues with arrival, orientation and locating the children's ward:

At the outset, parents emphasised that it is problematic getting a child with ASD from home to hospital as it inevitably necessitates a change of routine. In addition to the health issues behind the hospital visit, because the visit is loaded with numerous potentially stressful situations, anticipation of these by both the child and his or her family means that they are already likely to be stressed before they arrive. As noted by one participant,

> *"… some staff have very little idea about how much preparation needs to be made for the transition from home to hospital, the difficulties of just getting the child into the car to arrive at hospital, let alone needing to provide bowel samples, drinking awful tasting liquids and having the runs." (P1)*

Issues associated with parking were raised.

> *"A mum would arrive already feeling stressed, then worrying about $20 car parking, so trying to park on the road… then worrying when the clearway would be kicking in …. Ultimately having to park a fair distance away from hospital and walk. If there's two parents, perhaps one does the drop off and the other one finds a park." (P1)*
>
> *"If one parent and child is dropped off and other parent parks the car park, then the driver would enter at a different entrance; that can be a bit confusing on how to all meet up again ….there's an area outside the lifts and near the gift shop that you would arrive at if you came in from the car park, so if you'd been the driver and done the drop off, you'd probably need to turn back toward the main entrance to meet up." (P1)*
>
> *"Parking was fine and price was OK compared with other hospitals, but coming here reminded me of previous visits where things were not as straightforward. C3 was here for blood tests and I had to drag him through the car park." (P3)*

Other aspects of arrival were noted.

> *"The main entrance it's so busy - people being picked up and dropped off left right and centre with taxis and cars. And ambulances are parked... C1 would want to know why are there ambulances…it would be quite scary for him as you can see inside them."(P1)*
>
> *".....not knowing where to go and where to find the paediatric ward…needs a coloured line the goes on the floor directing people from the front door of the hospital to the paediatric ward…they have a system like this at Sandringham hospital which I found very helpful." (P1)*
>
> *"I was loaded down, carrying lots of heavy bags. I remember feeling really tired walking up to the children's ward which is quite a way." (P2)*

Initial impressions of the **reception area** were made.

> *"There's nowhere to sit (then C3 sees a bench just outside the main entrance) when your anxious and your knees start shaking one needs to take the focus away from standing." (C3)*
>
> *"Why does it look like a funeral home? (P1) It's not what I'd describe as a very approachable looking reception area....staffed by two serious looking men in white shirts and black ties."*
>
> *"The main hospital reception area could have more furniture so it looks nicer, a coffee table perhaps ….. the smell – it's very sterile." (C3)*
>
> *"Sitting in main reception can feel a bit crowded, admissions need to be quicker. It would be better if paperwork could be completed up on the ward when my daughter is more settled and has access to an iPad." (P2)*

A lack of clear **signage** in the reception area was raised by all parent participants.

> *"The only list visible is next to the lift, I can see 'Paediatric Consulting Suite' is that it?' there's no signs about paediatric ward in the reception area, I'll have to ask the receptionists." (P1)*
>
> *"It wasn't that obvious to find the way to the children's ward, I really had to concentrate and look intently over the lists." (P2)*
>
> *"This is a fair walk…. I can see a sign for paediatric consulting suites but nothing obvious for paediatric ward…. Hang on if I look hard at the small print of one of the signs I can see Area H - L1… does the L mean level? It's just that the numbers on the sign next to the lift presumably indicate floor levels, but they're not prefixed with an L, there is just a number… all a bit confusing". (P1)*
>
> C3 also reported that he found the signage confusing. *"I have finally worked out that we take corridor A/C."*
>
> Then down the corridor, near the mural he noticed a sign to Area C and commented *"Oh great, now we lose H*". He continued walking and at the information point, noted a sign with an H on it. With some excitement he exclaimed "*It points to a toy shop*" and was drawn across the corridor to check out the gift shop and its contents.

The **lifts** were identified as a particular difficulty.

> *"….you have to share normal lifts with patients who have just had major surgery. It happened to C2. She felt very self-conscious and told me it was a really upsetting and weird experience to share a lift after an operation. When she has been the onlooker, she's also felt very uncomfortable being in the same lift as someone returning from surgery" (P2)*

Walking down the **corridors** leading to the ward, it was noted that:

> *"The walls are bare and if there are pictures they are bland. Other hospitals corridors to wards are more child friendly." (P2)*
>
> *"I'd like to see more pictures on the wall, I call it blanking out when things are so boring. I like the tiles and blinds near café, they're nice and that outside bit is good. I would like to see more statues here" (C3).*

The importance of having an outside area available for patients to use was emphasised.

> *"If C3 is anxious then he can start to feel cramped and going into a courtyard would be a good option, the area is contained, not too big, just the right size." (P3)*

Passing by the closed doors of the small interview rooms on the way to the ward, P1 commented,

> *"C1 would be wondering are people in trouble, because it looks like a principal's office and kids with ASD are often sent to the school principal for issues with challenging behaviour." (P1)*

As he exited the lifts on level one, C3 noted and contemplated signage for 'Cabrini Foundation'.

> *"It looks flashy and I want to walk in there to discover more. It's more exciting than finding the children's ward." (C3)*

C3 positively noted more chairs in the corridor on his walk up to the ward. Following the sign, he headed toward the toilets. There is a sign located underneath the toilet sign that says 'This is area H, Level 1, ICU Waiting Room', he smirked and said *"well clearly it isn't, it's the ladies toilets."* He explained that due to his ASD, he is very literal and because of his Attention Deficit Hyperactivity Disorder (ADHD) he is drawn to things.

On seeing a radiation tester, then a sign with CSSD printed on it, he asked

> *"What does this mean? If I had more explanation this would make me feel calmer, I'm now wondering whether I need to go in there?" (C3)*
>
> *"What does paediatric mean anyway?... and signs that don't make sense, that say 'close only in an emergency' or 'exit' - but it isn't, it leads to ICU." (P1)*

Whilst walking along the corridors on the way to the children's ward, more triggers were noted.

> *"....beds left out in corridors make C2 feel nervous." (P2)*

> *"C1 would ask is this where my bed will be?" (P1)*
>
> *"C1 would get more anxious with all the distractions….: wheelchairs, trolleys, oxygen tanks…. very loud coffee machine in café, and sick looking people… actually seeing someone on a trolley would lead C1 to think, is that what's going to happen to me?" (P1)*

On passing ICU:

> *"There are distressed looking people sitting on couches and this would be quite upsetting for C1, who would probably think, if grown-ups are crying, maybe Mum hasn't told me everything." (P1)*

On the approach to the children's ward entrance, where lights are projected onto the wall:

> *"This could trigger an epileptic fit, why is it here? It doesn't make sense? …. I'm thinking a child might want to just sit down in the middle of the corridor and watch the lights to process what is going on." (P1)*

On arrival at the ward:

> *"….. I can't see reception, is it a camera, who sees it? ,… sign says wait for assistance, am I contacting security to let me in?" (P1). P1 was buzzed in and allowed access without actually speaking with anyone.*
>
> *"The buzzer at the entrance is very clinical." (P2)*
>
> *"That's a bit confusing… I so thought I would be talking to someone." (C3)*

Issues within the children's ward:

Within the children's ward, there are two general waiting areas for patients, one located in the day room and the other in the play room. The day room holds pre-and-post-operative patients from birth to 18 years of age.

The new day room was subject to numerous critical comments, in terms of both its environment and procedures.

> *"The new day room is a clinical and a scary environment for children and nothing like the old ward' (P2)*
>
> *"It's busy, loud, noisy and sterile looking and very bright, the lights can't be dimmed." (P1)*
>
> *"There are no pictures on walls and colours are dull. The ward is bland, not welcoming nor safe looking. Looks like a grown-up space/ room, not one for children… the children's ward at the RCH had themes of the sea and the forest, but this new ward is bland, it may have light shows on the walls, but they don't really make sense and are silly." (C2)*

> *“....there is no clock located where one would be expected – just above the receptionist. Instead there’s a crucifix, which I think is a bit unsettling for a child, given that there is nothing else on the wall to look at that is child friendly.” (P1)*

Newly arrived patients are directed to wait on a couch located in the corner of the **day room**.

> *“I don’t like this corner space- feels like ‘time out’ …. I like roomy.” (C3)*
>
> *“My child would want to sit on the very end of the couch closest to the corner and want me to sit very close to him and scrunch up into him for physical protection. This holding area in the corner of day room is quite small and not big enough for everybody, there could be six kids waiting, each with two parents, a pram and lots of bags. There’s been times where children have been constantly crying, feeling scared or really hungry, they haven't eaten since the night before and have missed their usual breakfast.” (P1)*
>
> *“Waited in (day) room for one hour surrounded by other families- even though we were first on the list. …was noisy and had children crying, they’d been fasting and were scared……this upset C2 and she got distressed started crying too.” (P2)*
>
> *“....it was just a corner, it was a joke. There were four other families waiting, not enough seats, no privacy, it was squashed and noisy and chaotic. The staff couldn't find the iPad, C2’s usual treat and this made her really upset.” (P2)*
>
> *“The day room accommodates a mixture of pre-and post-operative kids and they get upset when they are hungry and see someone else eating ice cream and fairy bread, they don’t understand that some have finished and that's why they are allowed to eat.” (P1)*
>
> *“We were here in the day room and a girl came back from theatre and was put in area close to us, C1 was upset at how sad she looked and asked what's happening to her, will that happen to me, where is she going to go now, will she be OK?” (P1)*
>
> *“Kids get iPad and TV when they sit in the big chair, so they want to sit there straightaway and get upset when they are told no and wait in the corner.” (P1)*

Participants voiced their concerns over the lack of privacy and the gadgets in this area.

> *“…. solid rooms feel more containing. …. curtains are not sufficient as they don’t allow for privacy…. separate cubicles are needed…. How do you manage children with special needs who might need changing?” (P2)*
>
> *“It’s quite confronting having all those gadgets on the wall behind where the child sits in the big chair, I wonder if they could be somehow covered over a bit….(P2)*
>
> *“….the cleaner’s room could do with having the door kept closed and having large cleaning equipment in the hallway is scary for C2” (P2)*
>
> *"I want to mess with all the buttons… the red and yellow colours pop out and I am drawn to them … the red cards grab my attention… the blue pump ….I want to hold it, look at it and fiddle…..these enclosures can be too open or too closed… look here, the curtains don't meet and it drives me nuts… it’s a bit bright but I like there is a light control.” (P3).*

> *"I find having that cleaning trolley left out in the hallway very distracting. I see lots of people but don't know what they are all doing" (P3)*
>
> *I am happy to sit and play on the iPad" (C3) "anything to help distract…. when he is looking at something, like an iPad then he is not listening." (P3)*

After an initial wait in the day room, patients are moved into the **playroom** to wait. Relocating from the day room to the playroom, participants walk past a room signed 'pantry'.

> *"At first when I saw it I thought, what is it? Who uses it? Can parents make a hot drink? Then I spoke with a nurse she told me it's the staff kitchen but staff would make hot drinks for parents ….. this relies on two things, that the nurse has a moment and you don't feel too awkward having to bother them when they have more important things to do … nurses also explained to me that the tea trolley goes around more regularly than it used to… but I don't see this as an improvement… as parents we are quite happy to make our own hot drinks and have a break from being bedside…. especially in the case of long stay admission ….it gives us an opportunity to mingle with others." (P2)*
>
> *"I think it's really important that a children's ward is fitted with a little parent coffee station rather than having to leave your child and go to the café." (P1)*
>
> *"In other hospitals (RCH, Monash) there is a family room in the ward allowing for a change of scenery." (P2)*

The playroom was also regarded as less than ideal.

> *"Children don't know how long they have to sit and wait and parents don't know either. Neither waiting areas have clocks." (P1)*
>
> *"C1 would make the point that the dayroom sign is incorrect, 'it doesn't have 8 chairs it has lots of chairs, if that's wrong, what else is?" (P1)*
>
> *"Lots of improvements could be made in here, hanging things on the walls, chairs for adults could be more comfy, there could be desks with chairs for children and this cream lino floor could be more comfortable." (P2)*
>
> *"My child did not feel safe in this area (play room) it was a vulnerable time, and it was bright, noisy, busy and at times even chaotic." (P2)*
>
> *"…the play space at the RCH was great for kids with ASD, there were activities fitted into the wall; tapping games and balls) … whereas this waiting room is messy and must drive the nurse's crazy…. there's a lack of exciting array of toys, just cars really… more toddler toys are needed and maybe an area- with iPads for the 16-year-olds." (P2)*
>
> *"I'd suggest including sensory toys like wooden discs and spike balls in the play room." (P1)*
>
> *"the colouring-in things need to be put out on the desks and books put on display, not away in the cupboard… the TV is really badly positioned and it doesn't have a remote control." (P2)*

> *"It's so noisy is in here. … look there's a television in the corner there, but you can't get to it as it's blocked off and there's nowhere to sit in front of it" (P1). …. someone else is playing on floor, they've already had a turn… I can so see the potential for arguments, children not taking turns at pressing the buttons, not feeling they can join in; wanting to press all the buttons at once…. pretty much doing things to upset other kids." (P1)*

Parent participants expressed concern about the **interactive wall/ floor**, particularly the balls.

> *"For people on the spectrum, this could lead to seizures...its easily done… on the old ward C2 started having seizures and it was later discovered that her trigger was the light filtering through the windy trees." (P2)*
>
> *"The (interactive) floor and wall are quite overwhelming, too bright, too noisy…. if C1 saw someone else already playing in here he'd get worried that he'd miss out and wouldn't be able to have his turn." (P1)*

When C3 was shown the playroom, he enjoyed using the interactive wall and floor, but commented:

> *"You'd have to warn people about this room. Tantrums are going to be thrown if people are forced to leave that room and the planet is not big enough for the tantrums that will be thrown!" (C3)*
>
> *"....parents will have to put in a warning before it's time to leave." (P3)*

Although it may be a great distraction and reward room for some, individual differences in a children's needs and reactions to environmental stimuli was also noted.

> *"The playroom would be confusing for C1 as he would not really be sure about what was happening and he would be nervous about his hospital visit… he'd just want a quiet and dark place to cuddle up with mum." (P1)*

The need for additional toilet facilities was noted by one parent.

> *"C1 would probably want to go to the toilet whilst waiting in the play room… I thought there might be one nearby, but after checking there isn't one, C1 would have to go back to the one in the dayroom. Don't appear to be many and they have to be shared by many patients and families waiting or recovering." (P1)*

After spending time waiting in the playroom, families are often returned to the dayroom and the child is put in a different chair.

> *"C1 would want the same chair as he had before - his chair, and now someone else would be sitting there. Then he'd get upset when he is transferred on to a big bed and doesn't want to go on it…I think at times like this ASD children could be given a weighted autism blanket." (P1) "Do they have heavy blankets here? C3 likes them a lot." (P3)*

Participants maintained that there was an urgent need for a **quiet** waiting area in the children ward where anxious ASD children can attain some calm. With very few options, nurses have suggested that the treatment room, if vacant, can be used as a calming area.

After surveying the treatment room, participant's comments were consistent:

> *"For an ASD child, this option is a disaster, a torture chamber as it contains all the scary things that could happen to you, cos' you've been in that room before for IV's and catheters." (P2)*
>
> *I'm surprised it's the only option available for ASD children to have a quiet space. It's not just the clinical trolley, the whole room is overwhelming. It is too bright, sterile, scary and full of instruments." (P1)*
>
> *"All that stuff on the wall makes me feel nervous. It's too open and bright, to be any good to me... it needs a dimmer light switch and an alcove area." (C3)*
>
> *"If this was used as a quiet waiting area for him, staff would need to be aware that the surgical bed could act as a trigger for anxiety. He hates lying down unless he knows it's a bed that he will be sleeping in. Hmmm …. asking him to wait on the bed.... well they'd have to recline him back really slowly, otherwise he'd get very upset." (P3)*

Walking into a **hospital room** with two beds, P2 offered details of her past experience of her daughter sharing a room.

> *"When my daughter has been a long term patient my husband and I have taken it in turns to stay over… so in here, where do parents sleep? There's no privacy…we all share a bathroom…. And look no fridge? That's not good." (P2)*
>
> *"There are new admissions who come and go… the lights are on and off….the other patient sharing her room had a large family and at one stage had 25 visitors…it was so overcrowded and noisy, it was awful and I couldn't hear C2 breathing to check if she was OK." (P2)*
>
> *"…would be helpful if parents were told pre-admission that 'headphones are welcome here' to assist with noise." (P1)*

When reviewing the single room, participant parents raised some concerns.

> *"This room looks cold and scary … the fold out bed is bad design…. it's too close to the patient if there is an emergency…. before the rooms were carpeted….*
> *This is not child friendly at all…. just look at the pictures on the walls, there are no themes for kids. There is overkill on the size of TV, how about having a smaller TV and spending more on decorating. The TV has no swivel- so if you are sitting on the parent's couch, you can't see the screen and there's no sound available for the parent as it is accessed via the remote next to patient's bed. What's that back curtain for? Bad for infection control…. anything could splatter and needs changing regularly. I think it would be good to cover the scissors and tubes behind the bed, maybe have a cupboard there." (P2)*

> *"When kids arrive back from theatre and are put into their room, there isn't a swivel on the TV, most kids want to watch some TV whilst cuddling with mum on couch …. it would also be good for mum to know at the start that the bed folds out for her, although when it is folded out it doesn't fit very well in the room". (P1)*

One of the respondents referred to the old children's ward favourably.

> *"The last ward was great, it was child friendly, there were stars on the roof; bubbles and the waiting room wasn't busy. C2 was immediately given an iPad, with YouTube on it and as she is not usually allowed YouTube it acted as a big treat for her and helped calm her down. The new ward is no longer located near the paediatric specialist rooms, where C2's gastroenterologist surgeon is located…. if surgeons needed to be asked questions they could be caught as they walked past. It's a different story now, this doesn't happen 'cos the new ward is a long walk away.'' (P2)*
>
> *''Also the old ward had a massive bath …. where is the bath in this new ward. It was needed to be able to wash C2 when she has tubes in." (P2)*

Disruption of routine and sensory challenges associated with a visit to hospital:

Having to go to hospital deviates from the child's regular routine and exposes them to an array of sensory challenges.

> *"There are lots of different smells, like cleaning and kitchen smells on the ward. They all affect sensory processing…. Actually, there's lots of things that lead to sensory overload... so busy, too many people walking around." (P1)*
>
> *"At 7am the clattering begins as the food trolley arrives and vacuuming begins. Senses will be working overtime for children with ASD, particularly their anxiety. At home, it is nice and quiet when C1 wakes up. When he receives breakfast at hospital; he says the toast is always cold which is a massive issue at home. The hospital needs to provide parents with better info about what they can ask for." (P1)*
>
> *"C1 just wanted to count the circles on the nurse's uniforms and then the ones on the wall… it was all a bit too much for him." (P1)*
>
> *"The nurse's uniform is so alluring…. I'm drawn in …. all those circles to count." (C3)*
>
> *"… the washing station doesn't work for me, it has no symmetry and uses different types of soaps in different sized bottles, why? They could all be the same." (C3)*

Any procedures involving **touch** may be perceived as invasive and unpleasant:

> *"…. putting on starchy gown with scratchy tags, labels and seams and ties at the back that are bumpy against the spine when you lie down…..C1 would want to take it off, which makes sense as it's uncomfortable. He is not aware of social embarrassment and would completely undress in front of others… bandages, tapes and dressings are also scratchy making kids want to rip them off too." (P1)*

> *"C2 gets nervous when it's time for her gown to go on as it feels uncomfortable and she knows it's time for surgery." (P2)*
>
> *".... sitting in the big chair they get a wristband. I've had mini battles with C1. He says they're hard and plastic and feel yucky, he cries out- I don't want it and you can't make me…. I wonder is there another way to put the wristbands on? Maybe give one to teddy, and mum and dad also… and is there is a less traumatic way to weigh children? When he looks at the weigh in chair, he says what a stupid chair I don't like it and won't do it." (P1)*
>
> *"When he is given a wrist band he just fiddles with it constantly…. asking him if he prefers lose or tight - give choices …. being more in control helps him to be less anxious." (P3)*

Importantly, **facing the unknown** is likely to provoke the child's anxiety.

> *"On a hospital visit, a child's faced with lots of unexpected things …they don't really know what's happening. C1 is a smart kid and he's very tech savvy, so ... he googles his operation beforehand. I must say 'operation ouch' is a great website to help promote kids understanding....it gives pretty accurate information about the procedure." (P1)*
>
> *"I can see that many difficulties associated with transition are rooted in neither child nor parent being fully aware of what is happening." (P1)*
>
> *"As a five year old- he attended Cabrini and was given a book regarding surgery with pics of what people look like… not sure if they still do that … that was good." (P3)*

As explained by P1, children with ASD often have a negatively biased prediction – a worst case scenario - of how things will turn out. She suggested the provision of clearer information and more certainty about what is happening may help minimise this difficulty.

Communication challenges:

Problems arising from the child's literal thinking and auditory processing difficulties were noted.

> *"Staff need to be trained to slow down and wait when they ask questions. Due to auditory processing difficulties, questions take longer to answer for children with ASD." (P1)*
>
> *"If a nurse says, I am just going to put some cream on and the child responds 'will it hurt?' And the nurse answers, it's like a mosquito bite, then a child with ASD who has a very literal understanding of what will happen will raise the point, but mosquitoes suck not bite; and it itches and lasts a day, is that how it will feel?" (P1)*
>
> *"…. another example is when nurses say it will help you go to sleep; then the child wonders will I wake up; I can feel things when I'm asleep; will I feel it; will I have a bad dream?" ….and being told it won't take long, needs to be more specific ….. when C1 is told he is going to theatre, he thinks it sounds like going to the movies." (P1).*
>
> *"… he thinks in pictures and if sign says 'do not stand', all he reads 'is stand on this', so it's better if signs say 'keep off' rather than 'do not'". (P3)*

> *“When C3 went into theatre I went with him and he just wanted to push lots of buttons, saying it was like a spaceship. Staff told him after the injection he'd feel ‘funny’, he thought he'd laugh.” (P3). C3 interjected “But I didn't laugh, I thought I was dying”.*

Difficulty in communication of **pain thresholds** was also raised.

> *“ASD kids can have difficulties accurately reporting the pain, they may ask for a band aid when they have a gash that requires treating with glue..... They have a ‘maths brain’ so we need to get rid of the number system, asking them to give a number to represent their huge anxiety is really difficult for them. It would be better to give them with a scale with sad or face showing pain at one end and a smiley face at the other.” (P1)*

Specific dietary needs was also emphasised.

> *“C1 is gluten intolerant. It’s difficult for children to see others drinking lemonade and eating fairy bread and jelly and not being allowed the same. I’ve discussed the feasibility of the hospital providing preservative free jelly, but was advised that this wasn’t able to be sourced in catering quantities.” (P1).*

Streamlining procedures and continuity of nursing care:

The importance of streamlining children with autism, from admission to discharge, was raised.

> *“There is a very real need to prioritise an anxious ASD child over others, so that when the time is ready for the child to go home, they are not waiting for physio/pharmacy. Get them up here ASAP from ED minimise anxiety/ distress about what’s going to happen and make it happen quickly.” (P1)*

The importance of **continuity of nursing care** was emphasised.

> *“I would like to see, if possible having the same nurse from admission to discharge as continuity is important.” (P1)*
>
> *“I worry about lack of continuity, when there are staff changes and no one passes on information… I also can’t emphasise enough the need for nurses be trained in sticking to rules ‘cos’ if you break one then you have lost trust.” (P3)*

Collaboration with parents:

Participants acknowledged the critical role played by health care staff. They strongly recommended that staff receive specialist training to enable them to effectively work with ASD children and that the importance of **collaboration with parents** is emphasised.

> *“Staff need to be educated to recognise the difference between a serious meltdown and a tantrum.” (P1)*

> *“it’s so important that staff listen to parents about where the child is at on the anxiety scale …I’m always trying to raise staff awareness of the non-verbal communication which indicates that he is really anxious… particularly noticing cues - I can see it in his eyes, so when this happens, the nurse needs to follow my lead, back off and come out of the room with me”. (P1)*

> *“It’s important to be able to have a private conversation with staff without the child being present. Just because the child is non-verbal it doesn’t mean they are non-hearing.” (P2)*

One of the parent participants commented specifically on the **journey to theatre.**

> *“Once on the trolley the child will be pushed from behind with mum and dad also following behind. If say a plastic steering wheel was attached to front it would give the child a bit of control in a situation where they feel they’ve none. I mean children could be directed by staff to turn left and right and steer the way.” (P1)*
>
> *“…. when the trolley is about to leave for theatre … the child doesn't know where theatre is and neither does mum….and there’s a one parent only policy and it is worth considering that perhaps the child will try and exert control as in ‘I want Dad rather that Mum’ …. so I reckon its helpful to try and plan ahead and using a ‘if this happens - then this’ response. All that matters is that one parent is there when the child wakes up.” (P1)*

The Hospital Passport:

The response from the parent participants regarding the hospital passport created by the National Autistic Society UK were very positive, although concerns were expressed about the extent to which this kind of resource would be utilized by staff.

> *“....looks good - I don't think I'd add anything really other than tailoring it to the local environment. It's the kind of thing I would love to see Amaze promote to parents, as well as directly from hospital units.... GPs, etc.’’ “My only concern is that like many tools we ASD parents provide to professionals, it could be ignored, if staff were not well trained on how to obtain, understand and use the information provided.” (P1)*
>
> *“I think the passport is a good idea but l do wonder if the staff will read it! With past experience of many hospital visits, l know that it can be very difficult to ensure that staff actually read information like this.” (P2)*
>
> *According to P3, “I really like the Hospital Passport. I think it is a great idea.”*
>
> *“I love the fact it states, don't change my medication without talking to this person. Medical practitioners love to change people’s medication because they believe that they know better. They don't understand that it may have taken years to get the medications just right. They may have a valid and better option but they need to have a good history before doing anything. The consequence can be catastrophic to the person and family/carers”. (P3)*

> *"There are a lot of things I would love to add to it. But in all honesty if it is much longer than it is, I don't think people are going to read it as it would take too long. They wouldn't look at any of the information and it is all really important that they get those crucial bits of information. So I think it covers all the really important things and everything else would really be learnt by talking to the person or the people they have nominated for the person to talk to". (P3)*

Summary

The participants in this study consisted of three parents of children with ASD, and one child (aged 12) with autism. Comments provided by the participants following a hospital audit, indicated several difficulties upon arrival, orientation and locating the children's ward. Changes to various places within the hospital such as waiting area's and corridors were recommended, such as adding furniture (coffee tables) and more child friendly pictures. Walking to the children's ward was fraught with many distractions and potential triggers of anxiety, such as high noise levels, trolleys/beds left in corridors and bright lights.

The children's ward and the new 'day room' prompted several comments indicating that these areas could be more child friendly, with a lack of privacy and distracting/calming gadgets for children also noted. The playroom was also regarded as less than ideal, with its bright lights and high level of noise. Participants made several recommendations about this room, with an emphasis on the need for more sensory toys. Similar comments were made regarding the treatment room, with the child participant reporting "*…the stuff on the wall makes me feel nervous*". Concerns were also raised about the overnight rooms, with participants again commenting on lighting and noise. These rooms were rated as not very family-friendly in terms of the room design, and the absence of a fridge.

Parent participants highlighted issues around the disruption of children's routines and their difficulties in facing the unknown. They emphasised the sensory challenges associated with a hospitable visit (e.g., in terms of being touched), as well as communication challenges (e.g., in communicating levels of pain). The importance of streamlining hospital procedures for children with ASD from admission to discharge to minimise anxiety was stressed, with parents also highlighting the importance of continuity of care (e.g., maintaining the same staff for their child if possible). Particular emphasis was placed on the importance of staff training, as well as the need for collaboration between staff and parents, to ensure the child's needs are understood. The sample hospital passport was well regarded by participants, although concerns were expressed about the utilisation of this kind of resource by hospital staff.

OVERALL RECOMMENDATIONS

Summary recommended strategies to address identified needs

1. ***Enhance collaboration between parent /caregivers and staff:*** The importance of collaboration between parent/caregivers and staff has been highlighted within the literature, by Cabrini staff members, and by parents participating in the hospital audit. Parents are the experts with respect to their child's anxiety triggers, what works best during a meltdown, and how best to communicate with their child. **It is recommended that parent/caregivers are consulted about and involved in as much of the treatment and the hospital stay as possible**.

2. ***Develop individually-tailored patient care plans****:* Individualized care plans are important to the provision of quality health care (Kopecky et al., 2013). **The use of individually tailored patient care plans are recommended.** The information included in the plan should be elicited from parents/caregivers during pre-admission processes, and include, for example, medical history, age at diagnosis, family details, how best to communicate with the child, strengths, things or words to avoid, anxiety triggers and strategies to assist with anxiety.

   ***'My Hospital Passport'* developed by the National Autistic Society, or similar, is recommended for consideration.** The passport contains personal information regarding how the patient would like to be communicated with, how they experience pain, things that distress the child and how they can be avoided, medical/ medication history and other areas such as sensory needs, rituals and special interests. It is designed to be kept with the child's medical chart, and disseminated to all staff who may provide care to that child. **If adopted, it is further recommended that staff receive training in the use of the passport to ensure maximum benefit from its use**.

3. ***Enable early identification of patients with ASD:*** In order to initiate parental collaboration and the development of individually tailored patient care plans, it is imperative that there is a system in place that enables the early identification of patients with ASD (or other developmental disability). Ideally this occurs prior to admission, but otherwise at any stage during the hospital visit (e.g., emergency department, ward, consultation rooms).

***It is recommended that the Patient Allocation System (PAS) enables a clinical alert or 'flagging' of patients with ASD* (or other developmental disability).** This system may also facilitate follow-up of patients and their families for purposes of service evaluation and other research opportunities for those who are interested.

4. ***Consider and adapt communication styles:* It is recommended that patient care plans include information on the form and nature of communication that works best for the particular child.** Given the issues which may arise from a child's cognitive ability, literal thinking, and auditory/visual processing difficulties, verbal instructions should be concrete, clear, logical in sequence, and given by one person at a time. The use of visual prompts is recommended.

   As recognized in the literature (e.g., Allely, 2013) and reported by parent participants in the current research, children with ASD commonly experience difficulty in communicating pain. **It is recommended that parents are consulted about their child's expression of pain and that visual pain measuring devices (e.g., pain thermometers) are used.**

5. ***Reduce common sensory triggers:*** A range of sensory challenges in hospital settings have been identified in children with ASD (Stagles, 2016) and were emphasized in the current research by staff and by participants during the hospital audit. **It is recommended that, where possible, efforts are made to minimize sensory overload**. For example, minimizing noise from the machines around the children's ward, minimizing trolleys and beds in hallways, and using indirect or filtered lighting where possible.

   The benefits of calming colours and minimizing repetitive patterns identified in the literature, together with the findings from the current research, suggest a review of the colour and pattern of the paediatric staff uniform. In particular, the symbols on the uniform were described as too busy, distracting and at times overwhelming, particularly where several nurses may be gathered together (at the desk or responding to an incident). In the staff survey, nurses reported that they had received requests from parents that they cover their uniform with a white patient gown before entering a patient's room, in order to minimize anxiety. **It is recommended that consideration be given to a change in the paediatric staff uniform**.

6. ***Employ strategies to minimize and manage patient anxiety**:* A change in routine and exposure to novel situations can be extremely stressful for children with ASD. A number of further recommendations are provided around strategies to minimise patient anxiety:

a) Keep readily available a **toolbox of toys and electronic hand held devices** and encourage the parent/caregiver to bring their child's specific preferred devices, so that children can have access to YouTube and other games which may reduce their anxiety levels.

b) Where possible, enable a **visit to the hospital site a week prior** to the child being admitted or attending for medical care. Develop videos showing a walk through common areas, equipment, such as gadgets, electronics and plugs on the walls behind the big chairs, and procedures that may be undertaken. These videos should be made available on the Cabrini website or sent to parents directly, so that parents and children can prepare for their hospital visit.

c) **Social stories** (a picture story concerning various hospital procedures or activities) should be made available in both electronic and hard copy form. These should be accessible within the hospital to a child who may find a particular procedure or activity anxiety provoking. They should also be available via the Cabrini website or sent through to parent/caregivers prior to attendance so that parents can read them with their child.

d) **Visual schedules** or an A3 visual board are also recommended for familiarization with the main stages of a hospital visit i.e., pre-admission and arrival, giving your name, getting a wristband, the playroom, returning to the day room, eating, and going home.

e) **A designated 'quiet' space** needs to be available for children with ASD to visit in order to prevent or assist them to cope with anxiety and in particular when they are experiencing high anxiety or an emotional 'meltdown'. This area should include access to sensory toys such and self-calming devices, e.g., electronic hand held devices and squeeze-balls.

f) The importance of **minimising wait times** was raised by both staff and participants during the hospital audit. To reduce anxiety, it is recommended that hospital procedures, from admission to discharge, be streamlined for patients with ASD, with priority status being given to them (speeding up admission and discharge time). Where possible, it is also important to **minimize the number of different staff** who attend to the child.

g) **Flexibility in procedures** was also highlighted in the staff survey. It is recommended that staff members undertake tasks in a "way that suits the family not the hospital." For example, to minimize anxiety associated with transition from one area to another, where possible, a child should have the option of being able to walk rather than being pushed on a trolley.

7. ***Make environmental adaptations*:** Participants in the hospital audit commented of the lack of child friendly designs in areas such as the 'play room', 'day room' and 'overnight rooms'. It is suggested that **more child friendly pictures** are added to the walls (e.g., underwater or jungle themes). It was also suggested that tables are placed in waiting rooms and more privacy is provided to patients in the day room.

   Clear **colour-coded signage** should be used so there is no confusion upon patient arrival in terms of where to go, and how to get to the children's wards.

   The need for **bench style beds** for parent/caregivers (as the double beds compromise space) and **fridges** for use during long term stays was highlighted by hospital audit participants.

   The availability of **family rooms** (alternatively used as waiting rooms, due to limited space availability on the ward) are recommended to allow patients a change in scenery. An outdoor area is also recommended to enable access to sunlight and fresh air by children who are in hospital for a long stay.

8. ***Increase staff training about ASD:*** The need for the provision of ASD training for all staff who may have contact with children with autism was highlighted in the literature (e.g., Golnik et al., 2009) and was emphasised in the findings from both the staff survey and the hospital audit. **It is recommended that training sessions in ASD are provided to staff by Cabrini hospital.** Training sessions should cover topics such as communication options, prevention and coping strategies for anxiety and challenging behaviours, recognising common 'meltdown' signs, and the importance of individualized care for a child on the Autism Spectrum.

   The focus of this review and report is on children with Autism Spectrum Disorders. It is important to emphasise that children with ASD vary considerable in terms of their presentation across areas such as communication, cognitive functioning, sensory and behavioural characteristics, and thus have individual needs. It is also important to acknowledge that many of the issues raised would likely apply, and the recommendations made may well enhance the experiences of other children, including those with anxiety and with intellectual and developmental delays. These are areas for future investigation.

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