A survey of experiences of parents of children with Autism Spectrum Disorder (ASD) attending CUH: how can we become more ‘Autism-Friendly’

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CARL Research Project
in collaboration with
Rainbow Club Cork Centre For Autism

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
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- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

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How do I reference this report?

Author (year) *Dissertation/Project Title*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: http://www.ucc.ie/en/scishop/completed/ [Accessed on: date].

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MX5091 – Research Project

A survey of experiences of parents of children with Autism Spectrum Disorder (ASD) attending CUH: how can we become more 'Autism-Friendly'

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Student Declaration: I hereby confirm that this work is entirely my own except where otherwise indicated. I am aware of the UCC regulations concerning plagiarism, and the disciplinary actions that may result. I have acknowledged the work of other authors as appropriate

Abstract

Title

A survey of experiences of parents of children with Autism Spectrum Disorder (ASD) attending CUH: how can we become more "Autism Friendly".

Introduction

ASD is a life-long developmental disability characterised by social and communication impairments. This makes the experience of accessing medical services very stressful for both children and their families. Despite higher than average hospitalization rates, the hospital environment is poorly suited to support this population's needs.

Objectives

To assess the standard of facilities available to families of children with ASD and to identify areas for improvement concerning their care in CUH. By gaining information from children with ASD who attend CUH, the availability, and the quality of ASD services they avail of, areas for improvement can be identified and recommendations can be implemented to make CUH more 'autism friendly'.

Methods

This cross-sectional mixed-methods study was carried out in cooperation with the Rainbow Club Cork Centre for Autism. The study population consisted of parents whose children accessed services at the Rainbow Club, the survey link was available on their social media pages and website. The survey contains open comment boxes for recommendations and five-point Likert scales to rate services on accessibility and quality. Patient identifiers are not collected.

Results

Responses indicate the need for improvements to services available for children with ASD. A lack of awareness of services that are currently available to children at present was also identified. Of the parents' survey, 18% of parents surveyed were unaware of any facilities. Overall the main areas for improvement identified are the Emergency & Paediatric departments.

Conclusion

These opinions and recommendations are be included in a monthly meeting of the Autism Friendly Hospital Working Group and taken into account when devising the strategy to make CUH an autism-friendly hospital.

Introduction

Autism spectrum disorder (ASD) is a pervasive and life-long neurodevelopmental disorder characterised by social, communication impairments and repetitive patterns of behaviour. (1). This can make the experience of accessing medical services very stressful for both children and their families. This unfamiliar hospital environment can often be overly stimulating for children with ASD. While some provisions are in place in hospitals across Ireland, more can be done to make our paediatric services, in particular, more 'autism-friendly'.

Background Literature:

Many studies have been carried out on this topic as the benefits of making the hospital environment more autism-friendly. By involving the primary caregiver in these decisions we can endeavour to implement the easiest, most accessible facilities for children with ASD.

Prior research has reported that youth with an ASD have higher utilisation of primary care (paediatric visits), specialty care (e.g., psychiatric visits, neurology visits), and acute care [emergency department (ED) encounters, hospitalizations] than youth without ASD. (2) (3)Frequent hospitalizations and medical appointments are often due to the high rate of comorbidities among patients with ASD. (4)Retrospective studies have shown that common comorbidities associated with an ASD diagnosis include gastrointestinal issues, eczema, allergies, asthma, ear and respiratory infections, seizures, and migraines. (5) (6) Despite the higher than average hospitalisation rate, the health care system is often not adequately supporting this population's unique sensory, behavioural, and communication needs. Such issues include overcrowded waiting areas and an overly stimulating environment on paediatric wards. (7) Issues such as those listed above can impact the healthcare that a child with ASD receives in the hospital setting.

Additionally, children with ASD develop a psychiatric comorbid disorder at a much higher rate than the general population. A population-based study from 2008 examined the prevalence of psychiatric disorders in 112 children and adolescents (aged 10 to 14) with ASD. (8) About 70% of the youth had at least one comorbid disorder and 41% had two or more comorbid disorders. (8) A recent meta-analysis from 2019 suggested that a pooled prevalence of 20% exists between ASD and anxiety disorders and 11% for depressive disorders. (9) This is notably higher than those reported in the general population. (10). The most common psychiatric comorbidities included social anxiety disorder, attention-deficit/hyperactivity disorder, and oppositional defiant disorder. (11)

Although knowledge and awareness surrounding ASD is increasing worldwide due to extensive research undertaken across many countries, these same studies have reported wide variation among healthcare workers in regards to diagnosis, prognosis, and management of autism. A study conducted in the United States showed great variation in opinions about autism even between specialties of healthcare workers. (12) When comparing beliefs held by primary care physicians (including family physicians, paediatricians) with those held by specialists in the field of ASD (child psychiatrists, psychologists), very different opinions regarding treatment and support for children with ASD were uncovered. These separate beliefs and lack of continuous staff education about ASD could prevent more recent research and developments in this field from being fully explored.

On a national level, the HSE has published the 'Report of the Review of the Irish Health Service for Individuals with Autism Spectrum Disorder', which aims to look further into potential improvements in this area. (13) This report advocates for annual service auditing to ensure improvements are being made to make healthcare more accessible for this population subgroup. By surveying the parents of the paediatric portion of this subgroup we have identified areas of hospital care to be improved in regards to staff education and facilities.

Furthermore, variations in the training received by healthcare professionals can lead to inequality in the care given to patients. An Australian study conducted in 2019 reported that 50% of hospital staff surveyed "felt uncomfortable and unprepared" caring for patients with ASD. (14) Further resources and training were recommended following this to ensure patient safety.

Implications for CUH:

Cork University Hospital (CUH) has endeavoured to be Ireland's first 'autism-friendly' hospital. This would see improvements in staff education about ASD, facilities available for this population subgroup, and increased awareness of ASD throughout the hospital. This process of improvement is being implemented by the Autism-Friendly Hospital Working Group. (15) This is an elected board of representatives from all healthcare modalities and members of ASD support groups and charities such as AsIAm, an organization working specifically with adults with ASD. This allows for progress and change across the hospital environment. Already, many measures are being implemented for patients with ASD. The Koala Room, a sensory room in the paediatric ward has been opened and improvements to the lighting and noise control in waiting areas have been made. Also, parents have been advised to wait in cars or outside rather than in a waiting room for outpatient appointments if easier for their child. This is to minimize the time children with ASD have to spend in an overly stimulating waiting area and to allow them to remain as calm and comfortable as possible. This study will survey parents to see if they have availed of any of these measures and ask how useful these changes have been.

While research and recommendations are needed from multiple populations such as adults with ASD and specialists on ASD, this study will survey parents of children with ASD. Primary caregivers of children with ASD are often left advocating or 'translating' for their child due to their verbal and communication impairments, therefore, they offer an insight into improvements to be made as regards hospital-based care.

Methods

Study Design:

The current study was designed to assess how primary caregivers (majority of participants were parents) to children with ASD felt regarding their children's interactions with healthcare services, staff, and facilities. To accomplish these outcomes, an electronic survey was administered (Appendix A). This questionnaire was developed specifically for this survey. The opening section of this survey asked participants questions relating to the frequency of presentation to hospital services over the previous 2 years. This also included assessing would Cork University Hospital (CUH) be their closest hospital and how often the child presented to CUH specifically in this period.

Additionally, parents were asked which departments they attended to allow recommendations to be implemented where children with ASD frequently attend. This included outpatient paediatric clinics, the paediatric ward in CUH, the Emergency Department & waiting areas within CUH.

A five-point Likert scale from 'strongly agree' to 'strongly disagree' was used to assess participants' satisfaction with current facilities available in CUH for children with ASD. It also asked participants to rate healthcare staff education regarding ASD in CUH and how staff interacted and communicated with their children during their hospital stay.

The final section of the survey utilised open comment boxes to allow specific recommendations from participants. Recommendations were requested for each of the areas of CUH listed above, and for overall improvements to CUH which would help us to become more 'autism friendly'.

The inclusion criteria for this study include: being the primary caregiver for a child who has received an official diagnosis of ASD. Participants must also either attend the Rainbow Club Cork Centre for Autism or interact with this organisation over social media. The sample population for this study, therefore, is the 280 families who use the Rainbow Clubs' facilities.

Participants:

This project was organised in conjunction with the Community-Academic Research Links (CARL) program in UCC. The CARL project works with the Rainbow Club Cork Centre for Autism to facilitate research that could improve the lives of children with ASD who attend their facilities. Therefore this survey was distributed electronically to parents of children with ASD who attend the Rainbow Club. It was made available on social media platforms including Facebook, Instagram, and the link was included in their monthly newsletter to community members.

Data Analysis:

Data were stored on a password-protected computer and participant identifiers were not collected at any point. Data were only accessed by the project supervisor and primary investigator. The data was cleaned, coded, and analysed using SPSS v27.0 (SPSS Inc., Chicago IL). The data collected from 5 point Likert scales were modelled on pictograms and bar charts to display results and review trends. The qualitative data collected was analysed using a coding inductive approach. Each answer was reviewed individually and trends were identified.

Study Ethics:

This study was approved by the Clinical Research Ethics Committee in University College Cork and was conducted with the permission of all participating organizations. No patient identifiers or demographics were collected. Participation was voluntary and consent was implied with the submission of a completed survey.

Project Timeline:

This project was carried out to fulfil the requirements of two modules: MX4090 and MX5091. The project commenced in October 2019 when the primary investigator met the project supervisor. The study design was conceived at this point and a comprehensive literature review was completed in January of 2019. Ethical approval was granted in June of 2020. Data were collected from November 2020 until April of 2021 and subsequently analysed and presented.

Results

A total of 47 responses were recorded. 2 responses were disregarded as the child did not have a formal diagnosis of ASD. Therefore 45 responses were analysed and have been summarised in this paper. All participants had a child who has been diagnosed with ASD and had attended Cork University Hospital in the previous 5 years. 20 participants (44.4%) reported presenting to CUH on an annual basis over these 5 years. 14 (31.1%) had presented 3-4 times over this period and 11(24.4%) had attended 1-2 times.

Facilities accessed in CUH

Participants were surveyed on their use of the current facilities available for children with ASD in CUH. This included services available for children with ASD or other sensory disorders in mind; such as the Koala Room, the sensory room in the paediatric ward, the sensory waiting room in the Emergency Department, and accommodations in place which can be availed of by any child with sensory issues or who is at risk of increased distress in a hospital environment. These measures include bringing a comfort item such as a soft toy to all appointments and spending minimal time in an overly stimulating waiting room by staying outside the hospital until being called indirectly for any outpatient appointments. Figure 1 displays the percentages of patients who availed of each amenity and aid. Overall uptake was quite low, 22.86% of participants had accessed none of the listed services on their previous visit to CUH. These facilities were available at the time of research. 18.57% of respondents had accessed the sensory room in the paediatric ward in comparison to 8.57% of those surveyed who availed of the use of the sensory waiting room.

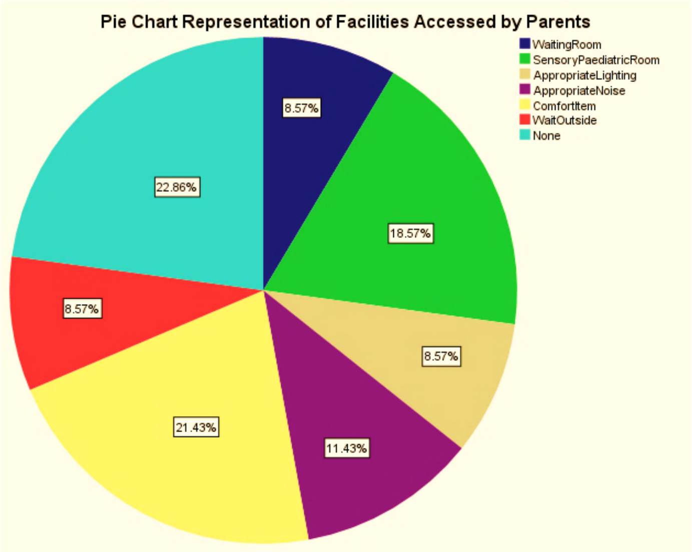

Figure 1 – Pie Chart showing the uptake of ASD facilities by respondents

Satisfaction with services and awareness of ASD in CUH

A five-point Likert scale questionnaire was used to evaluate participants' responses to statements concerning communication between staff and children attending CUH and their parents. This scale ranged from 'strongly disagree' to 'strongly agree' and answers are displayed in figure 2 below. Of those surveyed, 71.1% agreed with the statement "I was able to communicate with staff on my child's behalf in regards to their healthcare needs". In contrast, when asked to rate interactions directly between the child with ASD and staff members, the majority (75.56%) were unable to agree that adequate communication levels were achieved.

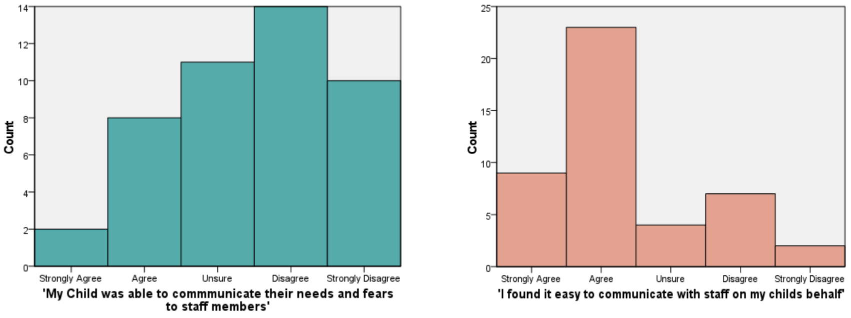

Figure 2 – Histograms illustrating participants satisfaction regarding communication in the hospital environment

Participants were also asked to evaluate the interactions between healthcare staff and their children. This included taking additional time to reassure the child, allowing them to adjust to the new, potentially overly stimulatory environment. The survey also asked were staff aware of additional stress which can be caused to a child with ASD under these unfamiliar conditions in the parent's opinion. These results are depicted in the below table. Answers varied across those surveyed with 57.8% of those surveys agreeing that healthcare professionals engaged with and reassured their child before performing procedures or examinations. Of those surveyed, 42.2% reported that adequate time was not given to allow their child to adjust to this overly stimulating environment before proceeding with examinations, resulting in increased distress for both the child and their parent.

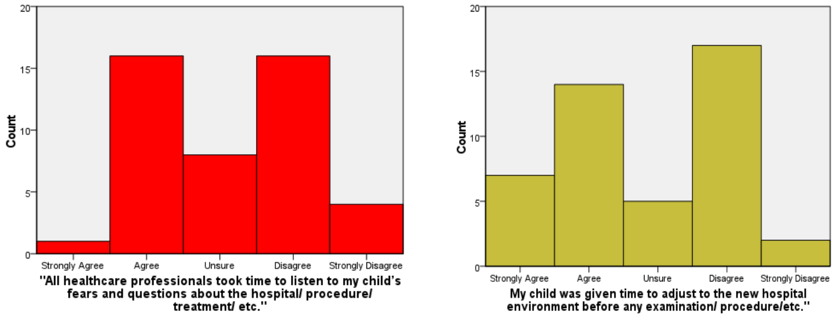

Figure 3 – Histograms depicting participants' level of satisfaction with healthcare staff helping their child adjust to the new hospital environment

<u>Satisfaction with quality of services when accessed</u>

As demonstrated in the figure below, when accessed participants overall found services to be quite satisfactory. However, deficits are obvious as illustrated by the large cohort who were unable to access or were possibly unaware of the existence of these facilities. Figure 2 illustrates participants' responses to statements evaluating services for children with ASD in the emergency department and within the waiting room within the hospital.

Additionally, participants were asked to evaluate how useful certain implemented 'calming measures' are within the hospital. These included the option to wait outside or bring a comfort item from home into an outpatient appointment. Higher recognition and approval rates were noted with these measures. 48.8% of participants rated the option of bringing a familiar item from home as useful or extremely useful. Similarly, of participants who availed of the option to wait outside for outpatient appointments, 51.6% rated this useful.

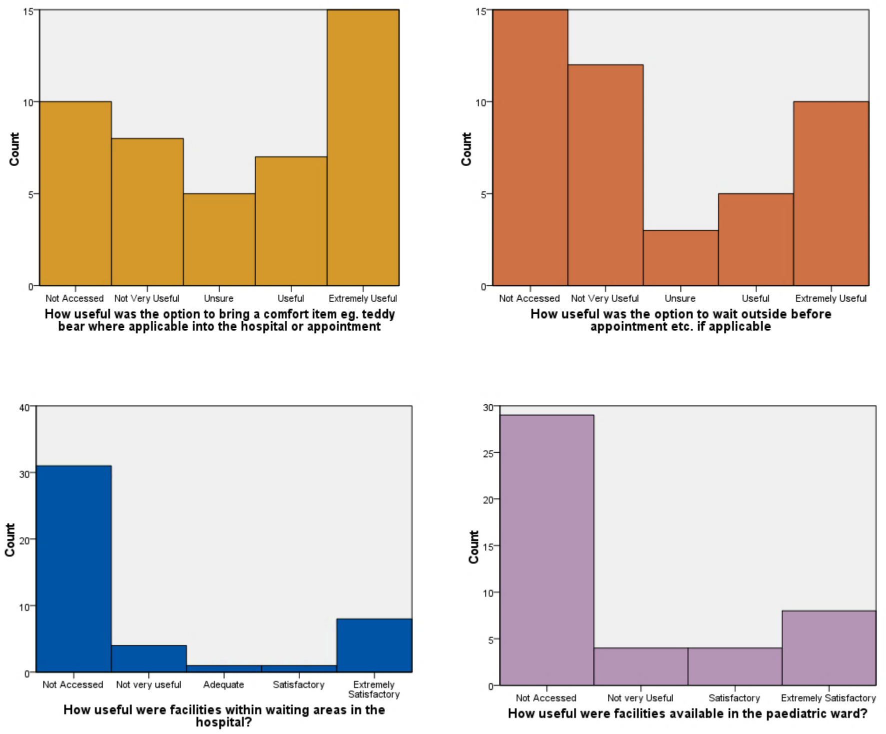

Figure 4 – Histograms showing parents level of satisfaction with ASD services in CUH

Satisfaction with individual, highly frequented departments in CUH

To identify where future services should be implemented first, participants were asked to rate individual departments within CUH on current facilities for children with ASD. The most frequently attended departments in this population are paediatric services and the emergency department. A five-point Likert scale was utilized within this questionnaire ranging from 'extremely adequate to 'extremely inadequate. A clear division was seen in satisfaction levels between the two departments.

62.2% of those surveyed were dissatisfied with the provision of services for children with ASD in the emergency department. 51.1% of those surveyed selected 'extremely inadequate' in response to this question. This clearly identifies the emergency department as an area for improvement when looking towards making CUH more 'autism friendly'. 31.1% reported being services available as adequate with only 6.67% being extremely satisfied with facilities currently available. In comparison, 62.2% of participants rated ASD-specific services within the paediatric department as being either 'adequate' or 'extremely adequate'. 22.2% rated these services as 'extremely inadequate' which may demonstrate an unawareness of facilities currently available or the existence of barriers to accessibility.

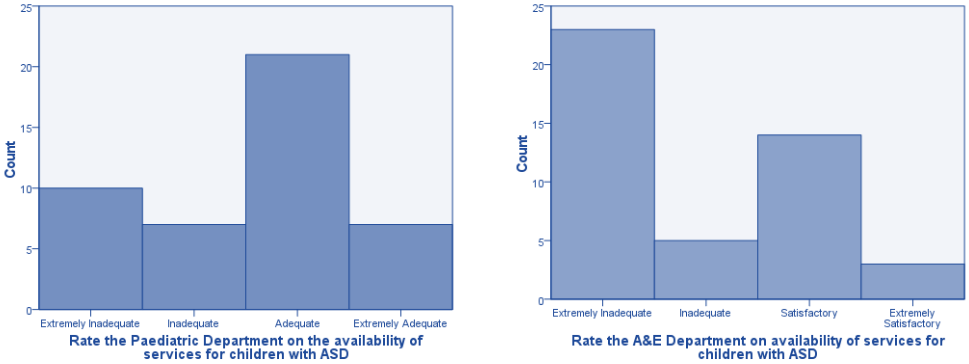

Figure 5 – Table illustrating participants' levels of satisfaction with individual hospital departments

Areas for improvement & specific recommendations

Qualitative comment boxes were included in the questionnaire to allow for direct, individual recommendations from participants to be collected. Prompts encouraged participants to pinpoint areas within both the emergency department, outpatient services, and paediatric wards in CUH which would benefit from increased facilities for children with ASD. Improvements suggested were categorized into main subgroups; communication, sensory environment, education, hospital organization, and identification of children with ASD.

Communication

As regards improving communication in healthcare settings, participants recommended increased training of staff on how to reassure and calm a child with ASD who becomes overwhelmed. Many also reported feeling "ignored" by hospital staff during consultations regarding their child's healthcare. As one participant replied, "Compassion goes a long long way for these patients and their families. We rarely worry about the procedures themselves. It's keeping our children from constant meltdown while in such an unfamiliar place with unfamiliar people. Our child is a flight risk and will try to leave the hospital while on a drip. Even rip out a drip. It is exhausting." This emotional account highlights the barriers to healthcare encountered by these families, as they struggle to reassure their children in such an overly stimulating environment.

Additionally, participants stressed the importance of communication between hospital-based care such as CUH with organizations such as the Rainbow Club. The facilitation of visual social stories to familiarize children with the process of attending the hospital in non-emergency situations was recommended to reduce distress. Examples are given included attending the outpatient department and also for use in explaining the steps of a clinical examination to a child with ASD, for example, to explain palpation of the abdomen. These social stories would familiarize children with the hospital environment and what to expect during a physical exam. "Social story for before the entire visit with pictures of the ward, some common hospital items and signs and even pics of staff and how they are dressed. Social stories can be added to the hospital website for various depts and procedures.", by adding such aids to the website, parents could help familiarize their children with the hospital before even attending,

Staff Education and Awareness

To allow for increased education and awareness of ASD, several areas for improvement were identified. Staff training would lead to increased understanding of ASD and the behaviours and "tantrums", as described by one parent, that can occur as a result. When asked for recommendations one parent replied, "Staff training in Autism and special needs. We had a nurse tell us we needed to be "more firm" with our son who was having a meltdown in A&E." This account highlights a lack of awareness of what a child with ASD experiences in the hospital environment. Further staff training could allow for quick identification when a child is struggling in their environment and moving them to the sensory area. The pressure would then be reduced on staff, parents, and most importantly, the child with ASD. As summarized by one parent, "Autism aware = a little more tolerance please and slow it down".

Identification of Children with ASD

Additionally, the implementation of a lanyard system to identify patients with ASD or similar hidden disabilities was recommended. This would alert staff that this patient may require extra time or assistance while attending CUH. Similar systems have been implemented in airports and supermarkets across Ireland with great success. (16) As one respondent noted, "Cork airport has sunflower lanyards to allow staff identify special needs customers. might be useful for cuh staff to have similar".

A similar recommendation included the implementation of 'hospital passports'. These hand-held health records would provide a written summary of any pre-existing medical conditions and regular medications. This would make consultations more efficient, particularly for children with ASD or other intellectual disabilities who may be non-verbal. Hospital passports would allow for easier identification of a child with ASD who may require extra time to adjust before a clinical exam or procedure.

Hospital Organisation

Recommendations to improve hospital organization for children with ASD included the development of a quicker pathway through the emergency department up to the paediatric ward when applicable. Also, a shorter wait time before outpatient appointments was identified as an area for improvement. Where feasible this may allow for a child with ASD to be seen as one of the first appointments in a routine clinic as this will reduce time spent in the waiting room. “Children with special needs cannot wait the long times expected of them. They are too upset by the time their appointment happens and it’s impossible to deal with the child and try and have a conversation with the doctor. There needs to be a better system for children with intellectual disabilities and autism. A child with an intellectual disability just simply cannot understand long wait times.” By shortening wait times and facilitating a quieter waiting area, children with ASD can be kept calmer and reduce the stress caused to them by this overly stimulatory experience.

Sensory Environment

The provision of extra distraction resources was recommended to improve the sensory environment. These included the provision of toys and technological aids to distract children during potentially distressing procedures such as phlebotomy. “Should have a quiet room for kids with special needs as ordinary waiting room can be overwhelming for them.”, this response indicates that often parents of unaware of facilities available for them to use. The Koala Room in the paediatric ward is specifically designed for children with ASD in mind, however, it is of no use if not properly sign-posted. Many recommendations were suggested to improve the waiting room in the Emergency Department. Parents mentioned, “Lower lighting. Working TV with dvd for long waiting times and not the news”. This account highlights the realities of children with ASD spending hours in waiting rooms. While often unavoidable, this experience could be improved by providing adequate sensory measures to prevent over-stimulation.

Discussion

This study demonstrates areas for improvements in CUH which would ensure it becomes an 'autism friendly' hospital. While many services are currently, this study demonstrates a scattered awareness of same by parents of children with ASD. The trends for improvement reflect similar aims as seen in the background literature and also those currently being examined by Autism Friendly Hospital Working Group.

Summary of Main Findings

- There is a lack of awareness of current facilities for children with ASD by their parents, signposting and promotion of these amenities are needed
- More staff education and training about ASD is needed, across all professions within the hospital
- Parents are very unhappy with the Emergency Department, which lacks facilities for children with ASD
- Improvements are needed in waiting areas in CUH for children with ASD
- Implementation of a scheme to easily identify children with ASD is needed

Comparison with Existing Research

The main findings of this study are in keeping with current literature on this topic worldwide. A recent study from Canada in 2014 similarly surveyed children diagnosed with ASD and their parents regarding accessing healthcare services. (17) Problems identified included communication and sensory challenges, and the degree of flexibility of healthcare providers and the hospital organization. These reflect the same areas of improvement identified in this study.

Similarly, a 2015 survey conducted with adults with ASD and their issues accessing healthcare revealed similar barriers as found in this study. (18) Research here supported the hypothesis that healthcare providers may lack knowledge and awareness of ASD, presenting a barrier to accessing services. This is also represented in this study through parents' lack of satisfaction at hospital staffs' interactions with their children, causing increased distress.

Major findings in a 2011 study have shown that children with ASD are more likely than neurotypical children to experience excess barriers to accessing healthcare. (19) This study also suggested that training programs for healthcare professionals to increase awareness of ASD would improve healthcare services for this population subgroup. This was similarly represented in participants' recommendations within this paper. (19)

Furthermore, when examining specific recommendations from participants, the background literature supports the implementation of many of these supports. A qualitative study conducted with caregivers in Northern Ireland examined the use of regional hospital passports for adults with intellectual disabilities. (20) The uptake of this hospital passport was welcomed by interviewees who recognized it as a tool for relationship building between this population and healthcare staff. Additionally, many participants in this study noted how the hospital passport alleviates stress for patients with intellectual disabilities in an unfamiliar environment as they do not have to answer repeat questions. (20)

Conclusions and recommendations within this paper also fit with the ethos of the Autism Friendly Hospital Working Group. This board within CUH meets monthly to discuss ongoing initiatives to improve the standard of healthcare delivered to individuals with ASD. This includes establishing "quiet spaces" for patients and their family members and training for staff. Similarly, they also recommend the implementation of social stories to prepare service users with a developmental disorder before attending the hospital. These recommendations were also noted in this study.

Looking nationally, AsIAm has been working to implement similar training schemes as recommended in the findings of this research. (21) The Autism Early Years Training Scheme, launched in 2019 aims to introduce ASD to early years educators and support staff who work with young children between 0-4 years. This training scheme consisted of informative talks from experts on ASD and workshops to solidify learning. A resource booklet was also provided to attendees providing advice on how to support young children with ASD. Over 60% of attendees recommended these workshops in follow-up feedback research. This scheme could be used as a model to facilitate staff education training about ASD in CUH.

Strengths and Limitations

This study was conducted with no observer subjectivity as the survey was completed anonymously. Furthermore, by collecting qualitative data we were able to record parents' individual opinions based on their experiences. This allowed for specific recommendations to improve CUH for children with ASD and for parents to feel involved in these improvements to the healthcare accessed by them and their children. Additionally, the survey is newly developed and tailored to facilities currently available in CUH. This allows for improvements that can be specifically applied to CUH to improve services.

Some limitations were encountered while undertaking this study. While an inclusion criterion for this study was that children must have an ASD diagnosis, participants were relied upon for this diagnosis, medical records were not examined. There may be time-related bias associated with these findings. Improvements and facilities for children with ASD are continuously being implemented in CUH and parents may not have attended CUH to avail of or experience this. Additionally, due to the COVID-19 pandemic, some facilities and services within CUH have been restricted due to the hospital adhering to social distancing guidelines. For example, reduced access to the sensory room may have contributed to parents' lack of awareness of this facility. This would impact responses related to ASD-specific facilities in CUH.

Similarly, due to the COVID-19 pandemic, the survey was moved to an online platform. Originally surveys were to be distributed in person, on select days to allow for a higher response rate and reduce population bias. An effect of moving data collection online is that this research does not represent those who do not interact with the Rainbow Club Cork Centre for Autism on social media or those not subscribed to their email mailing list. Furthermore, by moving data collection online we hypothesized a negative impact on response rate as there was now no direct contact with parents. This lower response rate may contribute to a potential population bias. Additionally, no patient demographics were collected. This does not allow us to target interventions and improvements to children who struggle the most. Further research is needed, for example, to identify which age children require the most supports within the hospital environment. Participants in this study were surveyed specifically on facilities in CUH, which means recommendations may not be applicable to all hospitals. As this study was conducted in a very localized subgroup, further research is also recommended in a wider population. This would collect further, more generalized recommendations for consideration.

Implications for practice

An increase in staff knowledge about ASD is the main area for improvement identified in this study. Training programs should be implemented for all staff members in CUH to improve understanding of ASD and the ways it can present in the hospital environment. Informed staff is crucial for those directly affected by autism who need support and intervention, as well as for their caregivers. Such training could be facilitated through an online learning platform. This would allow for staff to complete this training at their discretion.

Additionally, some measures introduced due to social distancing needs could be made permanent. Allowing children to wait outside for outpatient appointments rather than in a waiting area has benefitted many children with ASD and their parents. A return to a crowded, noisy waiting room seems unnecessary for this cohort. Where feasible, a similar procedure could be implemented across all departments to minimize time spent in waiting rooms.

Conclusion

Improvements must be made in the areas of education, awareness of ASD, hospital organization, and the sensory environment to ensure CUH becomes an 'autism friendly' hospital. This study provides useful recommendations which if implemented, where feasible, would remove the barriers to accessing appropriate healthcare that currently exists for children with ASD and other developmental disorders.

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Disclaimer

The authors have not or will not receive monetary gain from a commercial company or organization related directly or indirectly to the subject of this manuscript.

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Appendix A – Electronic survey administered to participants (Parents from the Rainbow Club Cork Centre for Autism)

Questionnaire

A survey looking at the experiences of parents of children with Autism Spectrum Disorder (ASD) attending CUH and what can be done to make Cork University Hospital (CUH) more autism friendly.

Chief Investigator: Dr. Louise Gibson
Medical Student: Nicole McCarthy

Section 1 - Frequency and purpose for visits to CUH

Please tick the appropriate box to indicate your answer.

Q1. How often in the last 2 years did you attend CUH with your child?	N/A	☐		
	Between 1 – 2 times	☐		
	Between 3-4 times	☐		
	More than 4 times	☐		
Q2. Would CUH be your closest hospital?	Yes	☐	No	☐
Q3. Over the past two years did you attend the inpatient department or outpatient department (day ward) with your child?	Yes	☐	No	☐
Q4. Over the past two years did you attend the Accident & Emergency department with your child?	Yes	☐	No	☐

Section 2 – Assessing availability of services

Q1. Please tick the box to indicate which services and facilities you availed of while your child was attending CUH

y waiting room ☐

y paediatric ward ☐

riate lighting in areas for your child ☐

Areas with appropriate noise control for you child ☐

Option to bring a comfort item e.g. Teddy bear ☐

Option to wait outside rather than waiting room ☐

Q2. Please underline or circle the option which most agrees with how you feel about the following statements.

My child found it easy to communicate their needs to staff members.

Strongly Agree	Agree	I don’t know	Disagree	Strongly Disagree

I found it easy to communicate my child’s needs to staff on their behalf.

Strongly Agree	Agree	I don’t know	Disagree	Strongly Disagree

My child was given time to adjust to the new hospital environment before any examination/ procedure/etc.

Strongly Agree	Agree	I don’t know	Disagree	Strongly Disagree

All healthcare professionals explained to my child what they planned to do in small, simple steps to ensure they weren’t overwhelmed.

Strongly Agree	Agree	I don’t know	Disagree	Strongly Disagree

Section 3 - Potential Improvements in Services

Q1. Please suggest areas for improvements from you and your child's experience in the waiting areas in CUH.

Q2. Please suggest areas for improvements from you and your child's experience in the Accident & Emergency department in CUH.

Q3. Please suggest areas for improvements from you and your child's experience in the Paediatric Department in CUH.

Q4. Please suggest any overall recommendations to make CUH more autism-friendly.

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4
Purpose or research question - Purpose of the study and specific objectives or questions	4
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	6
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	5
Context - Setting/site and salient contextual factors; rationale**	6
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	6
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	7
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	7
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	7
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	12
Limitations - Trustworthiness and limitations of findings	13

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	13
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	13