AutistiCare: A One-Stop Centre for Parents with Autism Spectrum Disorder Children in Perlis

Noor Azura Zakaria*, Nur Syazwana Tajuddin, Nur Faraayuni Sufea Mohd Supian

Dept. of Computer Science, International Islamic University Malaysia, Kuala Lumpur, Malaysia

*Corresponding author <u>azurazakaria@iium.edu.my</u> (Received: 18th June 2024; Accepted: 4th July 2024; Published on-line: 30th July 2024)

Abstract
— Individuals with Autism Spectrum Disorder (ASD) typically struggle with social communication and interaction, psychomotor, activity daily living, cognitive, as well as behavioural and intention issues. It is difficult for parents and carers of children with ASD to manage their difficulties, particularly at home and at school. This going to be worst if the parents or carers are not well-equipped with related knowledge on the ASD management. The COVID-19 pandemic situation that spread the world in 2020 has caused significant mental health challenges for parents, such as anxiety and depression, as a result of additional challenges in coping with their children in everyday life, in which the usual therapies that they received at the therapy centre must be completed at home. As a result, supporting them in managing this problem is critical to improving their psychological well-being as a continual attempt from the therapy centre to home. Society nowadays is adapted to the use of the technologies because of COVID-19 phenomena. Strong evidence suggests that online intervention is equally important with a face-to-face approach that has positive effects to autistic children and provides psychological support for the parents. However, there is a gap on the digital intervention platform according to the needs of parents for ASD management especially in Perlis society. Therefore, the purpose of this project is to invent a telehealth platform, characterized as the delivery of healthcare to patients and caregivers via the Internet. The proposed system is AutistiCare targeting parents with ASD children in Perlis that will be developed through a web-based system. The system includes various intervention modules, such as online communities, including online consultations between experts and parents, psychological support through forums, psychoeducation delivered via learning materials such as videos or modules, and service-related postings such as advertisements for ASD programs or seminars. It is envisaged at the end; the system is equipped with optimal ASD management content to support parents with autistic children in Perlis. In addition, it can be a platform to seek knowledge and assistance from the expert remotely.

Keywords— telehealth, Autism, ASD, digital intervention, online intervention

I. INTRODUCTION

Autism Spectrum Disorder (ASD) is a persistent and widespread neurodevelopmental disorder marked by in mutual social interaction, social communication, and the presence of restricted and repetitive behaviour [1]. ASD can be seen in early childhood, between 15 and 20 months of age [2]. As of now, autism spectrum disorder has no cure and individuals diagnosed with it must manage the condition throughout their entire lives. Children with ASD often face challenges in terms of behaviour, activity daily living, communication, cognitive, social, and psychomotor [1], [3]–[5]. In addition, children with ASD also often experience other symptoms such as sleeplessness, obsessions, self-injuring behaviour, and hyperactivity [2]. Therefore, an early diagnosis is crucially important to reduce the adverse effects caused by ASD by undergoing regular therapy sessions. However, with the presence of the pandemic Covid-19 in recent years, a lot of therapy centers have been shut down concerning the spreading of the virus. Consequently, this becomes an obstacle for the parents with ASD children to attend their regular treatment. This challenge is further worsened for individuals living in rural areas, where the closure of therapy centers may limit their already restricted access to essential services. For that reason, digital intervention is vital in helping to resolve the issue during the pandemic since the growing awareness of medical applications [6]. Learning from the Covid-19 situation, the acceptance of online learning is increasing because it can be accessed at anytime and anywhere. Hence, a digital intervention model for parents with ASD children in Perlis has been proposed. The proposed system is developed through a web-based system called AutistiCare which targeting parents with ASD children in Perlis. The system will help the parents and caregivers to cope with their ASD children's issues as this system provides the necessary support that can be accessed at any time and anywhere

as long as there is a connection to the internet. As a result, parents and carers will not be confused while dealing with their ASD children's behaviour, as this platform will provide a necessary intervention that can be done at home.

The rest of the paper is organized as follows: Section 2 provides the background of the study. Section 3 details the methodology. Following that, Section 4 presents the results, and Section 5 concludes with the findings.

II. BACKGROUND OF STUDY

According to statistics, the latest figure revealed by Autism and Developmental Disabilities Monitoring Network estimates that 1 in 59 children has been identified under the Autism Spectrum Disorder (ASD). In Malaysia, as reported by the Ministry of Health Malaysia, the prevalence of ASD in Malaysia was approximately 1.6 in 1000 based on the feasibility study on the use of MCHAT among children of 18 to 36 months of age in child health clinics. The above statistics show that an extreme movement should be taken to help improve the condition of people with learning disabilities, especially when involving ASD children. It is equally essential to assist parents of children with ASD in managing these challenges, as some struggle with controlling their children. Children with ASD frequently face challenges in terms of behaviour, activity daily living, communication, cognitive, social, and psychomotor [1], [3]–[5]. In consequence, it leads them to negative family outcomes such as increased parent stress levels, parent depression, and caregiver burden. Therefore, psychological, and social support are needed to manage child disorder. Although it is not possible for patients who have been diagnosed with ASD to recover from it, at least an effective treatment and intervention can improve a person's condition.

III. METHODOLOGY

The Iterative Software Process Model, which follows agile principles, was chosen for this project for its flexibility and ability to achieve measurable progress through small, iterative cycles. The focus of this methodology is continuous improvement and adaptability to requirements changing. This approach consists of seven phases that include planning, design, development, testing, deployment, verification and launch.

Phase 1: Planning

In this phase, we conducted a literature review on the telehealth component from existing literature and systems. We also collaborated with the stakeholders, which in our case, the experts in ASD and parents with ASD children in Perlis through an interview session to get the user requirements for the system.

Phase 2: Design

In this phase, we analysed the requirements and produce a use case diagram and flowchart for the interaction between the users with the system.

Design of the system

In this phase, the overall architecture and structure of the system are designed. It includes identifying the key components, modules, and their interactions within the system. We address the specific requirements of the system, such as providing support for parents, providing educational resources, offering online consultation between parents and experts, and pre-screening.

• Design of user interface

The user interface was designed taking into account the special needs and characteristics of people with autism spectrum disorder and their parents. The design should be intuitive, visually clear, easy to navigate and simple.

Design of use case

During this stage, the use case diagram has been produced. The system involves three actors in total who are parents, consultants, and system administrators. Figure 2 provides a visual representation of the use case.

Phase 3: Develop

After the design of the system was completed, the development phase took place. In this phase, we began implementing interactive prototyping to provide a tangible and dynamic representation of the system flow. For this purpose, Figma, a versatile design tool, was used, allowing our team to create an interactive experience that improved our understanding of system navigation and user interactions before diving into actual development. In the backend we used PHP as the scripting language and MySQL as the database management system.

Phase 4: Testing

After the system was completed, the test step took place. In this phase, we started testing the entire system functionality according to the system requirements. This step is required to identify the errors and verify that the entire application is working as per the stakeholders' requirements. Tests were also carried out to verify the performance, stability and usability of the system.

Phase 5: Deploy

In this phase, the deployment was conducted. It shows how the system functions properly in its environment, including installation, configuration, execution, testing, and making necessary changes before the product goes into production. The webserver and database server used for this purpose is Hostinger.

Phase 6: Review

In this phase, we conduct a review session of the final product with experts and parents with ASD children in Perlis to see whether it meets the needs of the stakeholders, whether the requirements are correct and whether the product works well.

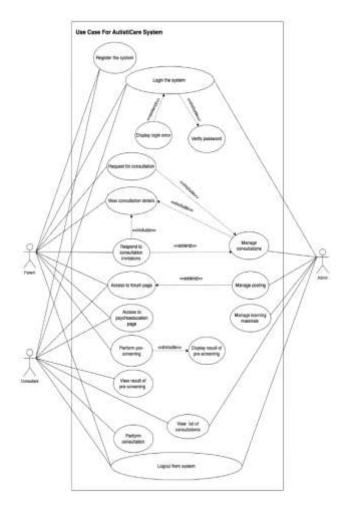


Fig. 1 Use Case Diagram

Phase 7: Launch

In this phase, we conduct a review session of the completed product with experts and parents of ASD children in Perlis to ensure that it meets the needs of the stakeholders, ensuring the requirements are correct, and additionally the product functions well.

IV. RESULTS

AutistiCare intends to promote the telehealth platform which is easy to be accessed by everyone at any location and at any time as long as there is internet availability. It leverages the conventional autism therapy to a digital platform. This is particularly advantageous for individuals in rural areas who may face challenges in reaching therapy centres. This is because the experts can provide one-to-one intervention plans when observing the children's behaviour through online consultation. Besides, parents and caregivers can stay updated on new modules through the system, allowing them to engage in ongoing interventions for their children with ASD.

AutistiCare is a web-based system that provides autism screening, digital intervention, learning modules,

and consultation with experts. It can be accessed from this link: https://autisticare.site/

Five features were provided which are service-related posting, online community (consisting of virtual consulting with the expert), psychoeducation (consisting of learning modules and videos), psychological support through an online forum between the expert and the parents, and pre-screening (consisting of assessment using M-CHAT questions). For the online pre-screening, AutistiCare will suggest the parents to meet expert to have further consultation to discuss about their children condition if the pre-screening results for their children indicate a high risk. It can be scheduled through online consultation with an expert in the AutistiCare website. Figure 3 displays the webpage of the online expert consultation that has two features – schedule consultation and view consultant details.



Fig. 3 Online consultation page for parents

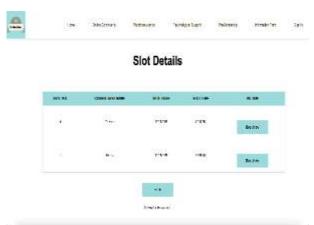


Fig. 4 Online consultation (slot details) page for parent

Figure 4 shows the available consultant's slot details for parents to choose to do the online consultation. The consultant is able to specify their available slot details as displayed in Figure 5 which will be presented to the parents.



Fig. 5 Online consultation (slot form) page for consultant

Figures 6 and 7 are related to the psychoeducation module that consists of digital intervention. It can be in the form of modules, videos, multimedia and many more. However, at this moment, AutistiCare only provides the modules and video as the learning modules.



Learning Modules

Fig. 6 Psychoeducation (learning modules) page for parents and consultant

Learning Material Videos

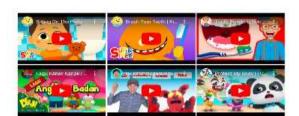


Fig. 7 Psychoeducation (learning videos) page for parents and consultant

Another modules provided in the system is the psychological support. The psychological support intends to provide a platform for the parents and carers to further discuss regarding any benefit topics, tips and experiences related to ASD management. It will be beneficial to other audience and readers. Therefore, a forum has been developed in the system as a support for the parents and carers who has ASD children.



Fig. 8 Psychological support (forum) page for parents and consultants

In the pre-screening section, there are M-CHAT questions, which consist of 20 questions as shown in Figure 9. Parents need to respond to all the questions, and the responses along with the results will be stored in the database. If the result indicates that the children is at high risk of having autism, then the parent can schedule an online consultation with the expert through the online consultation section.

Besides, parents can utilize the online modules and videos available in the psychoeducation section to consistently support and overcome issues faced by their children. Moreover, parents and caregivers can reach out to the community for help or post their concerns through the provided forum in the Psychological Support section. This method can encourage them to be more proactive about their children's issues.



Fig. 9 Pre-screening page for parents

Although the system provides a pre-screening section to help parents determine whether their children have autism or not, this may not be entirely accurate and it is recommended to seek expert opinions on the matter. Therefore, parents can arrange a consultation with the expert for a comprehensive assessment and diagnosis. The subject matter expert has the necessary intervention training to conduct a complete assessment taking into

account various aspects of the child's behavior. Therefore, seeking their expertise makes more sense as they provide useful insights into addressing the special needs of children with autism and promoting their well-being in the child's development.

V. CONCLUSION

In summary, the proposed AutistiCare web-based system meets the essential needs of parents and other caregivers of children with ASD in Perlis. Given the challenges of the COVID-19 pandemic and the increasing number of ASD, a digital platform is crucial. It emphasises the wide range of difficulties that children with ASD and their families face as well as the lifelong effects on individuals. The disruption of conventional treatment options caused by the pandemic highlights how urgent it is to find alternative therapies. Given these difficulties, AutistiCare, a web-based system solution, presents itself as an innovative and integrated platform aimed at supporting parents and caregivers in overcoming the challenges associated with ASD. The aim of the project with this integrated platform is to support families with autistic children in Perlis by providing the optimum ASD management content and improving the psychological well-being of parents.

ACKNOWLEDGMENT

This research was funded by Jamalullail Research Grant Scheme (JRGS) with project ID: JRGS22-021-0021.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

REFERENCES

- [1] American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders. American Psychiatric Association, 2013. doi: 10.1176/appi.books.9780890425596.
- [2] R. Oberleitner, S. Laxminarayan, J. Suri, J. Harrington, and J. Bradstreet, "The potential of a store and forward tele-behavioural platform for effective treatment and research of autism," in Annual International Conference of the IEEE Engineering in Medicine and Biology Proceedings, 2004, pp. 3294–3296. doi: 10.1109/iembs.2004.1403926.
- [3] O. Bonnot, V. Adrien, V. Venelle, D. Bonneau, F. Gollier-Briant, and S. Mouchabac, "Mobile App for Parental Empowerment for Caregivers of Children With Autism Spectrum Disorders: Prospective Open Trial.," JMIR Ment Health, vol. 8, no. 9, p. e27803, Sep. 2021, doi: 10.2196/27803.
- [4] S. Y. Chu, S. N. S. A. binti Mohd Normal, G. E. McConnell, J. S. Tan, and S. K. D. Joginder Singh, "Challenges faced by parents of

- children with autism spectrum disorder in Malaysia," Speech, Language and Hearing, vol. 23, no. 4, pp. 221–231, Oct. 2020, doi: 10.1080/2050571X.2018.1548678.
- [5] J. L. Matson, M. Sipes, M. Horovitz, J. A. Worley, M. E. Shoemaker, and A. M. Kozlowski, "Behaviors and corresponding functions addressed via functional assessment," Res Dev Disabil, vol. 32, no. 2, pp. 625–629, Mar. 2011, doi: 10.1016/j.ridd.2010.12.011.
- [6] Alnaghaimshi N. I., Alhazmi A., Alqanwah S. A., Aldablan M. S., and Almossa M. A., "Autismworld: an Arabic Application for Autism Spectrum Disorder," 2020 3rd International Conference on Computer Applications & Information Security (ICCAIS), 2020.
- [7] S. Hermaszewska and J. Sin, "End-user perspectives on the development of an online intervention for parents of children on the autism spectrum," Autism, vol. 25, no. 5, pp. 1234–1245, Jul. 2021, doi: 10.1177/1362361320984895.
- [8] A. S. Shminan, N. Fauzan, and M. Aren, "The intensity of the research activities on e-learning for care givers of autistic children," in 2015 International Conference on Information Technology Systems and Innovation, ICITSI 2015 - Proceedings, Institute of Electrical and Electronics Engineers Inc., Mar. 2016. doi: 10.1109/ICITSI.2015.7437682.
- [9] H. Huang, X. Hei, Y. Gao, and C. Zhang, "Design an applied-behaviour-analysis learning WeChat tool to assess the learning capacities for autistic children," in Proceedings of 2020 IEEE International Conference on Teaching, Assessment, and Learning for Engineering, TALE 2020, Institute of Electrical and Electronics Engineers Inc., Dec. 2020, pp. 333–340. doi: 10.1109/TALE48869.2020.9368393.
- [10] S. Bardhan et al., "Autism Barta A smart device based automated autism screening tool for Bangladesh," in 2016 5th International Conference on Informatics, Electronics and Vision, ICIEV 2016, Institute of Electrical and Electronics Engineers Inc., Nov. 2016, pp. 602–607. doi: 10.1109/ICIEV.2016.7760073.
- [11] H. Chai, "The Background of the Computer Information 3D of Fine Arts Instructional Materials on Autistic Children Effects and Individualized Language Intervention Training Under," in Proceedings 2021 International Conference on Forthcoming Networks and Sustainability in AIOT Era, FoNeS-AIOT 2021, Institute of Electrical and Electronics Engineers Inc., 2021, pp. 254–258. doi: 10.1109/FoNeS-AIOT54873.2021.00059.
- [12] L. Kashani-Vahid, M. Mohajeri, H. Moradi, and A. Irani, "Effectiveness of Computer games of Emotion Regulation on Social skills of Children with Intellectual Disability," in 2018 2nd National and 1st International Digital Games Research Conference: Trends, Technologies, and Applications, DGRC 2018, Institute of Electrical and Electronics Engineers Inc., Jul. 2018, pp. 46–50. doi: 10.1109/DGRC.2018.8712024.
- [13] A. Yakkundi., Dillenburger K., and Goodman L., "An inclusive reading programme for individuals with autism and intellectual disability using multi-media: Application of behaviour analysis and Headsprout early reading programme," 2017 23rd International Conference on Virtual System & Multimedia (VSMM), 2017.
- [14] S. Bardhan, M. A. Ullah, H. U. Ahmed, M. G. Rabbani, and K. A. Al Mamun, "Autism Express-a cloud-based framework for autism screening, confirmation and intervention," in IEEE Region 10 Annual International Conference, Proceedings/TENCON, Institute of Electrical and Electronics Engineers Inc., Feb. 2017, pp. 414–419. doi:10.1109/TENCON.2016.7848032.