

A Novel and Ubiquitous Early Intervention Support System for Down syndrome Children

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Abstract—Early Intervention Program (EIP) is very important in the overall development of children, especially to Down syndrome children. Trainers or teachers in special education field implement EIP in their daily teaching in order to improve the developmental abilities of Down syndrome children. In this study, a novel and ubiquitous Early Intervention Support System (EISS) will be created so that to assist the involved individuals in the implementation of this important program. The newly invented EISS consists of the Radio Frequency Identification (RFID) technology; computer based processing unit and the display unit. Besides that, the assessment test of the children ability is available in the internet to enable free access of the parents and teachers of Down syndrome children around the world at any time. The EISS will generate individual trainings based on input units, manage the user data effectively and provide the detailed information on Down syndrome to the users. This instrument is targeted to be used by teachers and trainers in special education classrooms or parents of Down syndrome children. In short, this support system is the ability to increase the implementation of EIP in Malaysia in order to improve the quality of life of Down syndrome children.

Keywords—Early Intervention Program, Radio Frequency Identification, Ubiquitous, Down syndrome

I. INTRODUCTION

Theoretically and generally, Down syndrome (DS) or also named as Trisomy 21, is a genetic disorder caused by the presence of all or part of an extra 21st chromosome. This special abnormality in the gene was first found by John Langdon Down and it is named after himself, who is the British doctor who described it in 1886.

The disorder was identified as a chromosome 21 Trisomy by Jerome Lejeune in 1959 [1]. Scientifically, the condition is characterized by a combination of major and minor differences in body structure. In the current society, Down syndrome is very often associated with some impairment of developmental abilities and physical growth as well as facial appearance. The learning progress of Down syndrome children is usually slower than the normal children.

Normally, children learn through observation and direct instruction. Several researches have proven that children who involve in the early intervention program (EIP) can improve the quality of their lives. For example in self feeding, a child who was not involved in EIP might only be able to feed himself at 7 years old, where a child who did involved in EIP can feed himself as early as when he is 3 years old [2].

EARLY INTERVENTION EFFECTIVENESS

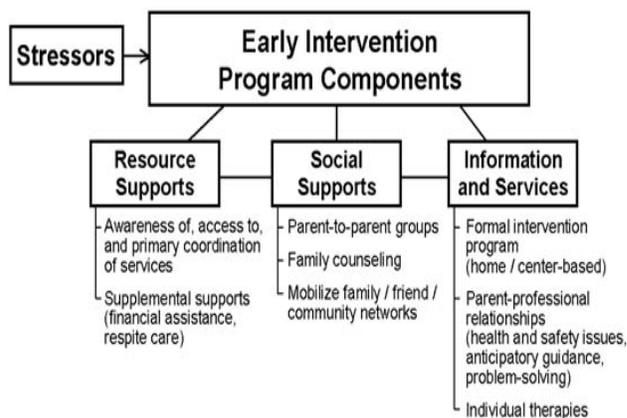


Fig.1: Effectiveness of early intervention for vulnerable children: A developmental perspective.

Fig. 1 shows the EIP effectiveness chart by Dr Guralnick. Dr. Guralnick's work focuses on the analysis of the effectiveness of early intervention techniques and programs for various groups of children with established developmental disabilities. According to him, the EIP is divided into 3 main components namely resource support, social support, information and services. Resource supports include the awareness and the access to and the primary coordination of services, and the sentimental supports. Social supports include the parent-to-parent groups, family counseling, mobilize family, friends and community networks, while information services include the formal intervention program, parent professional relationship and individual therapies.

Thus, it shows the importance of involving parents and teachers in the special education for Down syndrome children. An effective EIP requires a good cooperation of parents and teachers of Down syndrome children. Supports from the two important groups are crucial to improve the developmental abilities of Down syndrome children.

But, very unfortunately, EIP is not widely implemented in Malaysia. Most of the DS centers use “one size fits all” method to train the children. In other words, all the children in the centers will be grouped together based on their current ability ranges and they will receive the exactly same training. It is understood that the DS centers might not have enough man power for one to one training, but the group training does not suit especially to special children, as the learning progress of every child differ although they might be in the same age, and possessing similar ability currently.

Besides, the DS centers store children’s data and data analysis manually in logbooks. This is definitely an inefficient and not effective data management method. Trainers would also take time to analyze the data and generate the EIP, and the process depends heavily on the experience and the interpretation of trainers which might vary widely. In short, the problem in the implementation of EIP can be summarized as below [3]:

- Lack of standardized measurement instruments
- Lack of individual curriculum
- Insufficient information and
- Human resources limitation.

By realizing that the only promising solution to improve the quality of life of those with DS genetic

disorder is to provide them an effective Early Intervention Support System, we can conclude that the EISS is needed. The system should be able to store data, to update data and to analyze data (computerized).

Apart from that, this system should be able to generate individual EIP that consists of external training program and instrument based training which covers all important developmental abilities of children including the gross motor, fine motor, oral motor, cognitive motor and combination abilities. The system should also provide the optimal training duration for children where the optimal training duration is a function of age, medical data, motor data, cognitive data and combination data, target, training program, training requirement, as well as availability of facility, trainer and schedule [4].

Table below shows the main developmental abilities and the subgroups of each developmental ability included in the newly invented EISS

Table 1: Developmental abilities and their subgroups

| Developmental Abilities | Subgroups |
|-------------------------|---|
| Gross Motor | <ul style="list-style-type: none"> • Head movement • Rolling • Sitting • Standing • Crawling • Walking • Running • Jumping • Multi-movements |
| Fine Motor | <ul style="list-style-type: none"> • Visual contact • Arm movement • Fingers coordination • Holding object • Body movement • Locating objects • Writing |
| Cognitive | <ul style="list-style-type: none"> • Perception • Concentration • Logical thinking • Memory |
| Language | <ul style="list-style-type: none"> • Vocalize ability • Verbalize ability • Express thoughts and feelings |

| | |
|------------------|---|
| | <ul style="list-style-type: none"> • Communication • Understanding communication |
| Social emotional | <ul style="list-style-type: none"> • Social • Emotional • Play |
| Self help | <ul style="list-style-type: none"> • Feeding • Dressing • Personal hygiene • Daily activities |

II. LITERATURE REVIEW

The Learn at Play Program (LAPP) has been done by G. Iaroci, N. Virji-Babul, P. Reebye, S. Fawcett [8] previously. It is an Early Intervention Program for infants with Down syndrome and their families that is grounded in the developmental systems (Cicchetti, 1984; Sameroff, 1992; Sameroff & Chandler, 1975) and ecological perspectives (Bronfenbrenner, 1979).

According to the researchers, the main goals of the program developed were to optimize and support the development of social competence among children with DS. LAPP incorporates five key components- etiology-specific evidence-based practices, transdisciplinary team to facilitate parent-child play and teaching opportunities, a relationships among parents, clinicians, researchers, and the provincial Infant Development Programs, aimed to help parents to optimally use community services and to ease family life transitions, for example, the child's entry into the school system and an evidence based approach to incorporate longitudinal data collection to chart periods of development when marked changes in social competence are expected to occur.

The research findings provides us the identification of the interventions that work best for whom and at what period in development to optimize social competence in the child and family well-being and hence, are used to evaluate and improve the model.

Generally, individuals with Down syndrome (DS) who are having the high risk for Dementia of the Alzheimer type (DAT) live at areas remote from major medical centers. Hence, telemedicine is a modality for medical care at remote locations but according to research, it is still underutilized for populations with

Alzheimer disease (AD). A study was carried out by Ira T. Lotta, Eric Dorana, David M. Walshb and Mary Ann Hille [9] to determine the feasibility of using telemedicine to evaluate symptoms of DAT in 90 individuals with DS.

It is shown that the difference in average cognitive scores between a telemedicine and traditional academic medical center-based clinic site (TAC) were tested using 2-way analysis variance with site and premorbid IQ as factors. Components of the neurologic, imaging and neuropsychological examinations differentiated subjects with and without DAT ($p=0.008$) irrespective of whether a subject was evaluated at a telemedicine or TAC site. Thus, it is concluded that it is not impossible to make a diagnosis of DAT in DS by telemedicine. This study supports the need for formal reliability and validity studies of telemedicine preparatory to the consideration of this modality for use in clinical trials for AD.

In the special education field, it is known that Early Intervention Program (EIP) is required to improve the overall development of DS children. In order to help trainers and parents in the implementation of EIP, a support system has been developed [4]. The developed support system is able to screen, store and analyze children data, then generating individual EIP curriculum with optimal training duration and generating training automatically. The support system consists of hardware and software, where the software prototype has been implemented and tested using JAVA language and Linux Fedora. The support system was tested to ensure functionality and reliability. Test results show that the system is reliable to generate individual curriculum which includes the training program to improve the motor, cognitive, combination abilities of DS children under 6 years old.

However, the developed system can only be used for onsite training. In order to accelerate the EIP implementation in Malaysia, to improve screening and training methods through the data sharing as well as to manage the DS related data in Malaysia for service quality improvement purpose, a ubiquitous support system is developed and implemented in Malaysia.

These can be implemented through the integration of developed support system in tele-education and telemedicine network. These network infrastructures have been implemented by researches and institutions in Malaysia [6] [7].

III. METHODOLOGY

The development of ubiquitous EISS for Down syndrome children under 6 years old was carried out in 3 phases

Phase 1: Field and Literature Surveys

In the first phase, we had surveyed on the affordability of the Down syndrome related organizations, experts, parents and trainers in terms of their financial capabilities. Besides, we also surveyed on the Down syndrome centers' infrastructure and the parents as well as trainers' abilities to use computer based ubiquitous system. Those surveys are important in order to ensure the EISS developed can be fully utilized for the implementation of early intervention program.

Then, we surveyed on the availability of the early intervention support system in Malaysia and the companies or government that may support the implementation of ubiquitous EISS in Down-syndrome centers and Down-syndrome families home. Furthermore, the regulation from ministries or related acts was also studied to avoid conflicts with the ministries or violating any law in the country.

The surveys was carried out in centers, organizations, government sectors, companies, parents and trainers' community as well as schools for Down-syndrome. The surveys were done through three methods including visits, distribution of questionnaires and interviews. The survey results were recorded and analyzed. The outcome of the surveys shows us the affordability of the Down-syndrome related organizations centers for the setting up of the ubiquitous EISS infrastructure and the implementation of the system to help the Down syndrome children. Besides, we also found out the quality on EISS in Malaysia.

After that, we browsed (online) the worldwide organizations related to Down-syndrome, Down syndrome research results and papers, Down-syndrome activities as well as weblogs of the trainers and parents. Besides, we searched for the online teaching and learning for Down syndrome children and online software for the early intervention support system implementation. We also explored the web service development for data integration and management as well as implementation.

The result of this phase includes requirement of EIP implementation and extracted information, which were used to improve the available EISS and integrated with ubiquitous EISS that has been developed.

Phase II: Development of Ubiquitous Early Intervention Support System

First, it was the realization of EISS Network Infrastructure. This infrastructure was developed as tele-education infrastructure in laboratory. The infrastructure consists of data base center (web server), home work station, training center work station, school work station, medical center work station, non-government organization work station and government work station. The network was implemented through wireless and wired connection.

The second step was the testing of EISS network infrastructure includes stability, reliability and safety. Then the online user interface was developed. After that, we developed the EISS database server. We transferred the available EISS's content to the mentioned server. We also integrated the EISS content with the survey results obtained including the requirement of EIP implementation in Malaysia and the worldwide collected data. We used software XML and JESS for user interface and data connector.

Next, we developed the user data access system for home, training centers, non-government organization (NGO), government and school. The connection between user and database server was developed by using open source software.

In this phase we also developed ontology for smart data extractor. At the end of this phase, we improved the safety, reliability and user friendliness of online EISS which includes the encryption and data backup.

Phase III: Testing and Improvement

In this phase we have conducted two type of testing, whereby one was laboratory testing and the other one was field testing. For the laboratory testing, we tested the system on several aspects for example the functionality, safety, user friendly, compatibility, and reliability. On the other side, we have carried out field testing at Down syndrome centers, children's homes, NGOs, governments and schools.

Besides that, we have also tested on the user accessibility, and achievement of requirement from users (teachers, trainers and parents). For both testing, we prepared the test procedure, test forms and any other related documents. After the testing, we analyzed the test results and improved the system based on the analysis result. Then, we did the final testing in the fields.

IV. DESIGN AND IMPLEMENTATION

In the ubiquitous EISS that we have developed, the most important part is the software. Complete and reliable software was developed to input, store and display, and update the user data. Also, the software is able to generate the individual curriculum with optimal training durations; as well as to give instructions and analyze the results as part of screening and training.

As referred to few famous researches in this field, the system is designed to analyze the input data by comparing the DTA with the references data that are collected from literatures [1] [5], Down syndrome centers, trainers, parents, experts, and self assessment. The system screens data automatically, store and analyze the data, as well as producing curriculum. The data processing is programmed using JAVA language, the outputs of the system are individual curriculum in printed form, memory data, and instrument based training program.

After the software developed, it is uploaded in the internet and the data collected are all saved in the EISS database server.

Some of the Graphical User Interface (GUI) of the support system is as shown as below:



Fig. 1: The front page of the Ubiquitous EISS for Down syndrome children under 6 years old.



Fig. 2: The Children data list registered



Fig. 3: The assessment part of the EISS developed

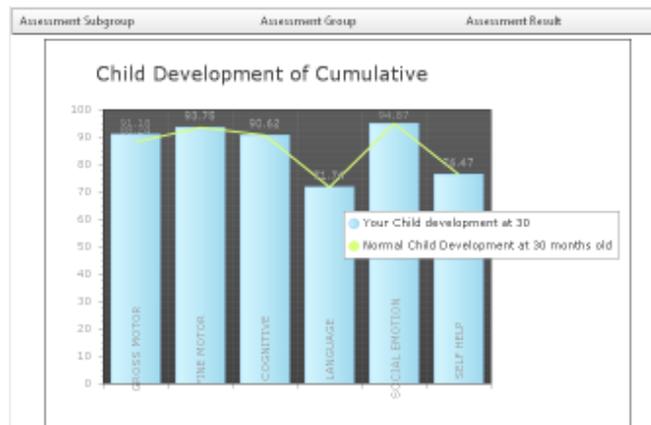


Fig. 4: The results of children ability assessment in graphical form

The results of assessment are presented in graphical form. Several graphs including graphs of subgroups in the six main developmental abilities are also available. After we have obtained the results of assessment, the suggested training curriculum for each child specifically

will be provided. Parents or trainers can train their children according to the suggested activities. The suggested training might involve the use of RFID technology to make the training process more interesting and effective. The configuration system is as shown in Fig. 5 and the main flow of the support system is as shown in Fig. 6.

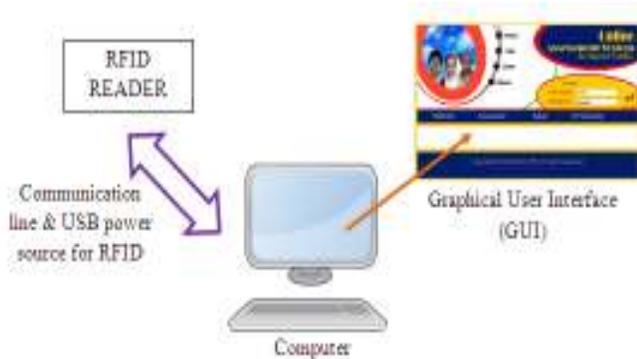


Fig 5: The configuration system of the Ubiquitous EISS for Down syndrome children under 6 years old developed.

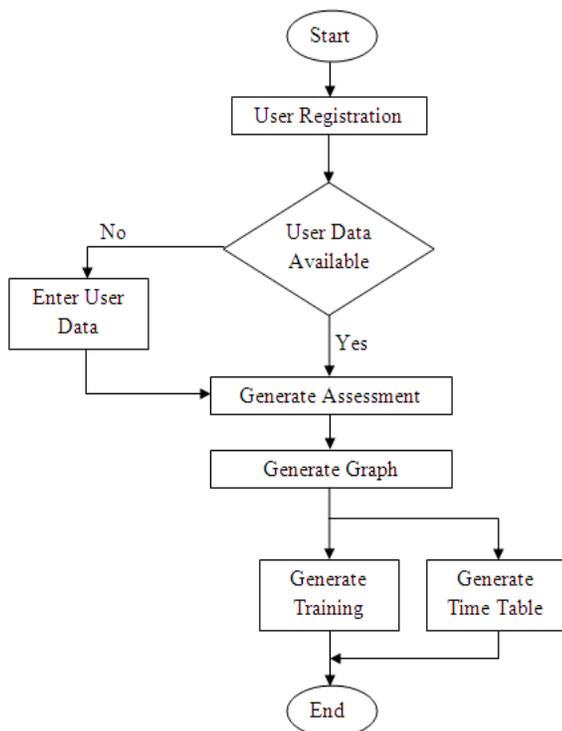


Fig 6: The main flow of the Ubiquitous EISS for Down syndrome children under 6 years old developed.

Apart from the software part, the content in the support system is also an important part that we have considered. The contents of the support system are

based on Hawaii Early Learning Profile (HELP) and Denver Curriculum. Due to the reason that curriculum used in Europe and America might not be suitable in Malaysia, we have also edited the curriculum based on the needs and requirements of the Malaysian culture. The editing part is referred to experts and professional trainers in the Down syndrome center. Hence the reliability is ensured.

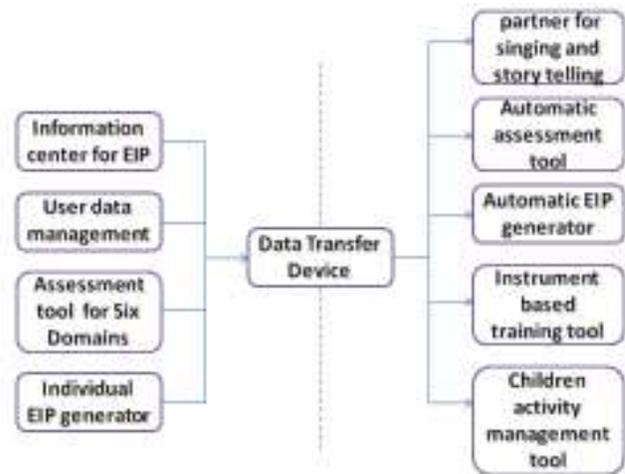


Fig 7: The integration between EISS developed with the training tool in future

Fig 7 shows the integration of the EISS developed with training tool which can be developed in the future. According to the figure, the left hand side of the figure shows the function of the EISS developed and uploaded online. The EISS is able to provide information on EIP to the parents or trainers of Down syndrome children. Besides that, it serves as the user data management tool where all the children data registered will be saved safely and retrieved easily. EISS is also able to scan the level of the developmental abilities and then prepare an individual curriculum for a particular child.

The results of assessment and the curriculum generated can be saved in a data transfer device, for example USB drive. Then, the data is transferred to the training tool to perform training on the children. In order to increase the efficiency of the training process, the training tool serves as the children's partner for singing and story telling. Besides that, the training tool might also consist of sensors such as RFID sensor, infrared sensor, and some other sensors for training purpose. Assessment will also be done after training to evaluate the improvement of the children.

Apart from the sensors, the training tool needs to be equipped with camera, speaker and microphone in order to make it more interactive and enable supervision of parents from another working space during the training of the children. The training process will be recorded and analyzed by the trainers or parents so that the next training which is more suitable and effective for the children can also be manually designed.

V. RESULTS AND ANALYSIS

The surveys in phase 1 have given us a good idea on the rules and regulations on the special education in Malaysia. Besides that, it gave us a better perception on the infrastructures and the need of EIP to be implemented in Malaysia. Some useful information from website was also extracted in the phase 1 in the research.

Also, as mentioned in phased 2, the development of the EISS is based on the findings in the phase 1, together with the implementation of software language and internationally recognized curriculum. The database is saved in the server and updated from time to time to ensure the relevant information and training is provided to the user.

After the software is completed, two tests are being brought out. The first test is the laboratory testing where the functionality, safety, user friendly, compatibility, and reliability of the EISS is being tested. The support system which is available in the internet is proven to be able to function well, user friendly and safe to be used by the users.

Besides that, the program was also brought to the Down syndrome centers for field testing on the user accessibility, and reliability. Positive feedbacks were collected from the centers. However, minor changes on the software in order to make it easier to be used as in response to the feedbacks from the parents and trainers.

VI. CONCLUSION

The ubiquitous early intervention support system for Down syndrome children under 6 years old has been developed in order to help children with Down syndrome to improve the developmental abilities with the use of RFID technology. The support system also used for user data management in Early Intervention Program.

The developmental abilities of the children are divided into 6 domains including the gross motor, fine

motor, cognitive, language, social emotional and self help abilities. This support system emphasizes the software and also the curriculum used to assess and also to train the children. The results of assessment is shown in graphical form in order to allow the parents or trainers to see the difference in the development of their children as compared to the normal children and then provide suitable curriculum and training to the children.

The main advantages of the system include the simplicity of the system and the utilization of interesting interface to the assessment and training process. It is interactive and able to attract the attention of children.

For future works, it would be beneficial to develop a support system that consists of other electronic components, for example, more RFID tags for gross motor, fine motor and cognitive abilities assessment and trainings, microphone for language ability assessment and training, and also videos and songs for social emotional and self help assessment and training.

VII. ACKNOWLEDGEMENT

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