Original Paper

Development of YOUSAY the Information Sharing System for Families of Children with Autism Spectrum Disorder

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Abstract

In this project, we developed an app named YOUSAY to help share information among people in close contact with children with Autism Spectrum Disorder (ASD), taking best advantage of the advent of iPads. In their daily lives, ASD children and their families have much contact with specialists. Therefore, their families must often provide information in various formats to ensure understanding by each and every specialist at various institutions. With its many functions, however, YOUSAY records, processes and provides a vast amount of information necessary for the welfare of ASD children. YOUSAY records the likes or dislikes of the children and how to deal with them in accordance with eight sensory characteristics plus the category tagged Circumstance. It also keeps track of daily occurrences like a diary and basic profile of the children concerned. Among many other advantages, YOUSAY has the search function, printout function, and save-as-PDF function that are not possible with written material. We believe that YOUSAY has the capability to act as the information-providing tool for people from all different walks of life in order to gain a greater awareness not only of the difficulties but also of the strengths of ASD children.

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1. Introduction

Children with Autism Spectrum Disorder (ASD) have, according to the Diagnostic and Statistical Manual of Mental Disorders 5th Edition: (DSM-5) published by the American Psychiatric Association, difficulties with social communication and are prone to repetitive/restricted behavior (RRB)[1]. Thus, ASD children cannot help but experience difficulties in forming communication and interpersonal functions in various social situations, e.g. at schools or hospitals. Diagnostic criteria for ASD in DSM-5 include factors involving the senses, which is why we focused on the sensory characteristics as stimuli that ASD children receive from outside their own bodies. It is quite often that the public in general mistakenly regard an ASD child's thoughts and actions derived from the child's sensory characteristics as the result of improper discipline given out by the child's family members. In addition, it is very difficult to discern the sensory administrated characteristics of an ASD child from the child's countenance and appearance, so that the family members have difficulty in providing expert supporters with the correct information needed. Therefore, it is urgently demanded that we contrive an efficient system of information sharing, in appropriate correspondence with each and every stage throughout life, to improve the daily circumstance in which ASD children and their family members struggle to live.

Many ASD children live in communities with their families, just as children with normal development do, growing up as they pass through day care centers or kindergartens, schools, and hospitals. At each of these places, ASD children and their families deal with many specialists and professionals. However, even family members may find it difficult to know the sensory characteristics of ASD children, making them give up even trying to communicate in sudden situations. As a result, the families of ASD children frequently record and submit through various documents information to make the staff of different institutions understand the characteristics accompanying the disabilities of their children[2]. However, the vast amounts of information provided are not shared between the institutions involved, and even within the same institution, information may not be properly shared between staff[3,4]. Currently, municipalities and local governments use a support book as a tool for sharing information on the children[5]. In the support book an ASD child's family members record dislikes that are triggers for panic and things that interest the child. The book is shown to school teachers, primary care doctors and other adult carers for the child. However, it takes a long time to record and update handwritten notes of all the vast amounts of information on the child in the support book. And, as the volume of information increases, it becomes more and more of a chore for the family to search for the necessary information and maintain it. The heavy weight of the support book also means that it is often not carried with the child and is hard to consult when needed. Obviously, there is a need for a more convenient tool that eases the burden of informing people during everyday life of the characteristics of the ASD child.

Many initiatives and studies are being undertaken in order to support ASD children in this way. The TEACCH program[6] aims to improve the quality of life of the ASD child and the family via treatment and education for comprehensive lifelong support. The PECS cards[7] support communication by using picture cards, playing a major role in helping the children to communicate their choices. In studies using ICT (Information and Communication Technology), Jowett et al.[8] use the video function of iPads to teach the basics of writing the Arabic numerals; improving the ability to write the numbers 1 to 7 recorded on the app. Flores et al.[9] created the Pick-a-Word app using photos in a similar way to the PECS cards as a communication tool, verifying the feasibility of this using five pupils. Work in this way is ongoing to improve the communication skills of ASD children, particularly through training and support involving the children. In order to ensure the correctness of this support, the families must accurately convey information on the ASD children to the relevant specialists.

The authors have collected a wide array of information on the condition of and issues involving ASD children and their families from several specialized occupations involved in the community. Our studies have focused on three points: (i) the desires of the ASD child's family in terms of providing information; (ii) how to organize this information; and (iii) what sort of support tool can be devised from the previous two

points[2,10,11].

In this project, we developed an app to facilitate the sharing of information on ASD children between those involved in their care, using smart devices. This app reduces the burden on the families of ASD children and shares information on difficulties and ways of dealing with them according to the children's sensory characteristics, so that they can receive the proper services.

2. Methods

2.1 Development environment and policy

We formed a team consisting of seven people from varying occupations: (i) four people with experience of working with ASD children and their families (nursing, schooling, psychology, social welfare); (ii) two people with experience of information processing and systems administration for support of people with disabilities in the local community (information, engineering); and (iii) people with experience in creating information communication tools for ASD children (design).

After receiving approval from a university ethical review (15-015, 15-086), we held interviews with families of ASD children. The various occupations then analyzed the children's sensory characteristic difficulties and the families' methods of dealing with them, after which we designed an information sharing app. The interviews were conducted (from September to December in 2014) by experienced workers with five members of families with ASD children under 18 years of age. In addition, data was gathered from records and notes kept from birth for one child.

2.2 Needs revealed by interview results

2.2.1 The vast amounts of information

For each single sensory characteristic, information continues to be revised and added to as the child develops, making it hard to keep track of via hand writing. It is also difficult to organize this information and communicate it verbally to others.

2.2.2 Information isn't being shared

As an example, the family has to rewrite and resubmit information on the child each time that the teacher at the school changes.

2.2.3 Important information isn't stated

Peculiar behavior by the child may be noted, but the reasons behind this behavior may be hard to understand. Care-givers want information focused on problems, hence the recorded information tends to take on a negative view: the child's dislikes, trouble they cause, or failures. However, there are reasons why the child acts or speaks in a certain way. There are also positive factors as the child grows.

2.3 Specifications of the app

2.3.1 The sensory characteristics

There are eight sensory characteristics (Vestibular Sensation, Vision, Audition, Olfactory Sense, Taste, Visceral Sense, Touch, and Proprioception), plus a further category for Circumstance.

2.3.2 Likes and dislikes for the sensory categories

For each sense, the ASD child's likes and dislikes are recorded. For audition, for example, this would mean sounds that they like or dislike.

2.3.3 Ways of handling dislikes

The dislikes are paired with methods used by their family to dispel the child's unease. Using audition as an example again, the app might record data as follows:

Dislike: emergency drills

Response: if the locality where the child lives is planning to hold emergency drills, take the child somewhere else.

2.3.4 Device used

As smart devices are widely used by ordinary households nowadays and owned by many people, we opted to use Apple's iPad as the device to keep daily records for the family of the child. For the development of the app, we used FileMaker Pro 14 by FileMaker Inc. We used this for its high degree of affinity with electronic patient files, in consideration of information sharing with medical institutions.

3. Results

3.1 Profile of the developed app

In this project, we developed an app called YOUSAY. With this app, families of ASD children can keep records of the child on iPads. YOUSAY allows the families to record dislikes or things that disturb the child for each sensory characteristic, and also how the family responds to these situations. The child's preferences or things they are good at are also recorded for each characteristic. A diary of everyday occurrences is also maintained, along with a basic profile of the child including the child's primary care hospital and medicine. YOUSAY can be used on the iPad by installing the free software FileMaker Go and then forwarding YOUSAY.

3.2 Screen layout

3.2.1 Top screen

Figure 1 shows the top screen of the app we developed. This is the first screen displayed when the app is first launched. The main function of this screen is to show the menu and transition to other screens. The buttons on the screen are: [Like • Dislike], [Diary], [Diary list], [Like • Dislike list], and [Setting]. Each of the buttons transitions to another screen. Selecting [Like • Dislike] transitions to the Like • Dislike screen. [Diary] goes to the Diary input screen, [Diary list] to a screen listing diary entries, [Like • Dislike list] to a screen showing the entries' input on the Like • Dislike screen, and lastly [Setting] takes the user to a profile of the child. Figure 2 shows these screen transitions.

3.2.2 Like • Dislike screen

Figure 3 shows the Like • Dislike screen after transitioning from the top screen. This screen is for recording information on the child for each of the sensory characteristics. It contains a menu to select which sensory characteristic to record for. Once a sense is selected, the app transitions to a screen to input information for that characteristic (Figure 4). Selecting [Top page] returns the user to the initial screen. Selecting [Profile] on the lower left of the screen takes the user to the child's profile screen. A photo of the

Figure 1　Top screen of YOUSAY, the app developed for this project

child is shown in the space above the [Profile] button.

In the input screen shown in Figure 4, the child's likes and dislikes for each categorized sensory characteristic can be recorded, as well as solutions the family has taken according to the nature of the disliked situation. The data is saved after input by selecting [Preserve]. If the user wishes to redo the input, [Delete] erases the data.

3.2.3 Like • Dislike list screen

Figure 5 shows a screen listing entries of data recorded in the input screen in Figure 4. Users can view saved likes, dislikes, responses and categories (recorded sensory characteristics) on this screen. The accumulated data is shown as a list and can be printed out by selecting [Print]. Users can enter keywords to search for by selecting [Search]. [Sort] arranges the data according to sensory characteristics.
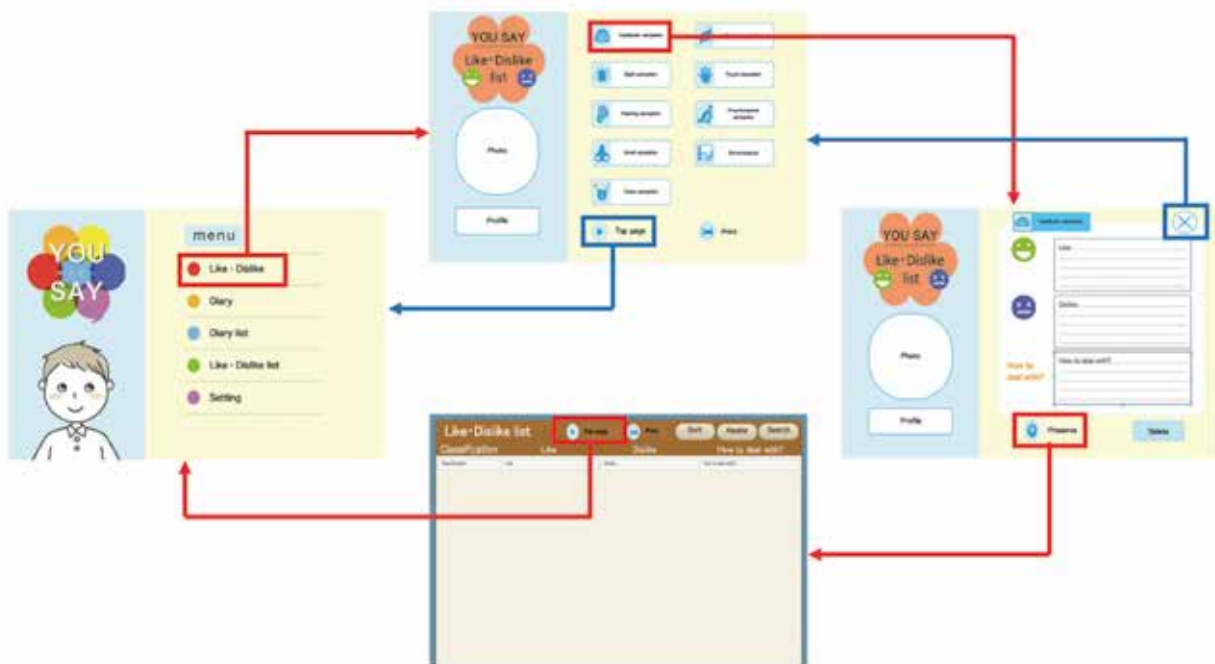

Figure 2   Screen transition from the top screen

Figure 3   Screen to select the sensory characteristics

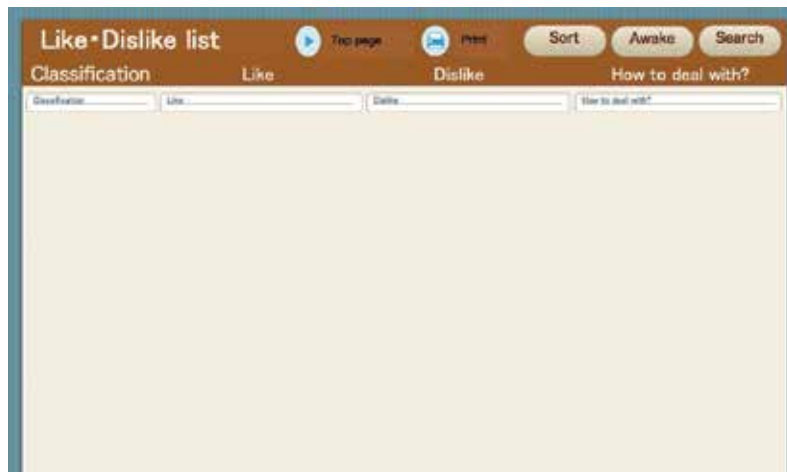Figure 4   Example of input screen for likes and dislikes
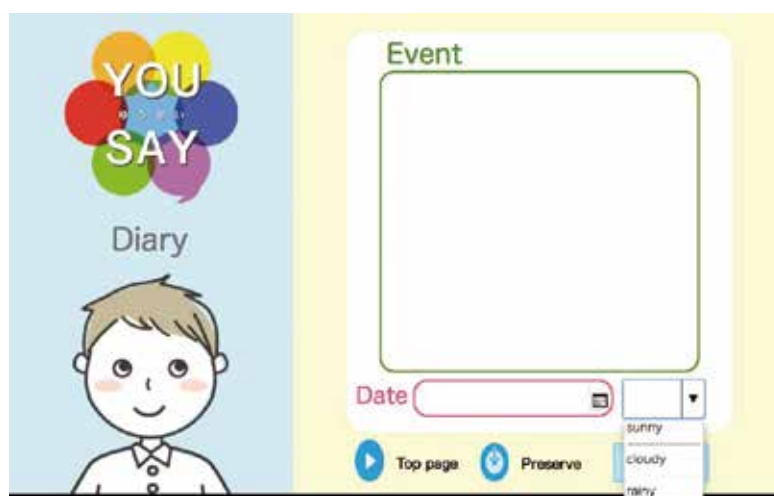
Figure 5   Like・Dislike list screen

Figure 6   Screen for diary input

3.2.4 Diary screen

The diary input screen to record diary entries is shown in Figure 6. The family members can freely record information on their child here. They can describe what the child ate, the child's health, or efforts or ideas that the family comes up with. The date of the entry and weather are also recorded. [Preserve] stores the entry, and [Delete] removes the selected data.

The Diary list screen has the same layout as the Like • Dislike list screen, and also displays a record of the date, weather, and diary entries in a list. Selecting [Print] on this screen allows the content to be printed out.

3.2.5 Setting screen

Figure 7 shows the child's profile screen, displaying personal information on the child. The information recorded on this screen includes the child's date of birth, age, diagnosis, primary care hospital, medicine, contact information, family structure and photos. The date the information was recorded is saved as the registration date. Data is stored by selecting [Preserve]. When the profile is updated, a history of the changes is kept without overwriting the data. When the user wants to change the information, they select [Edit] to edit and overwrite the entered data. The profile history list screen has the same layout as the Like • Dislike list screen, with each profile item being displayed on the list. Selecting [Print] on this screen allows the content to be printed out.

3.3 Implemented functions

YOUSAY has the search function, printout function, and save-as-PDF function that are not possible with written material. Figure 8 shows a comparison between written material and YOUSAY.

These functions can be used on the Like • Dislike, Diary, and Setting list screens. On these screens, the vast amounts of data stored can be filtered by word searches to display only the necessary information to better manage the child's records. The required information can be located and printed out for submissions to schools and hospitals. It can also be saved as a PDF, allowing data forwarding via email or social media to share the information.

3.4 Evaluation

Trials of YOUSAY were very well received by professionals involved with ASD children as well as their families. Schools and hospitals want different types of information. With the support book, it was difficult to easily summarize and submit the particular information each wanted. YOUSAY makes it possible to print
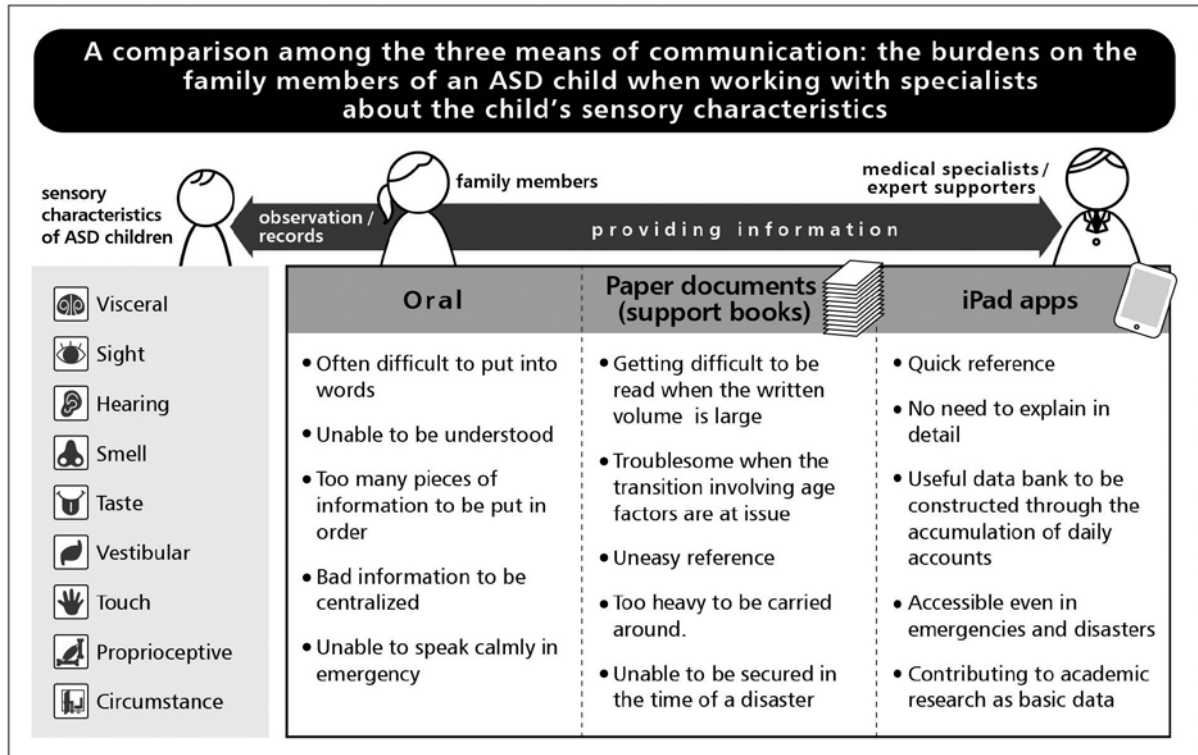

Figure 7 Child's profile screen

Figure 8   A comparison between oral and written support and YOUSAY

out only the information that is needed. As a result, many people commented on how effective it was for information sharing.

Other comments noted how YOUSAY made it easier for specialists to understand which senses the child is sensitive to, by sorting its records according to sensory characteristics. Advice for improvement noted that terms such as "Vestibular sensation" and "Visceral sensation" were somewhat difficult for ordinary people, and that using "Looking" and "Hearing" might be easier than "Optic sensation" and "Auditory sensation".

Many users noted that the app was not difficult at all to operate, as they already made use of smartphones on a daily basis. Some parents who were only used to Android terminals did say that they took some time to familiarize themselves with the controls. Another point made was that it would be easier if the like or dislike could be entered first prior to selecting the sensory characteristic.

Users were happy with the pastel colors of the screen design. They also noted the relaxed atmosphere of the screens and the characters, making it easier to accept. Some stated that the brown color of the list screens seemed rather somber.

Others pointed out that, in a disaster, it might only be possible to take one's wallet and mobile phone, leaving the support book behind, but if YOUSAY was installed on their smartphone, they could still continue to use it.

4. Discussion

4.1 Providing and sharing information for ASD children

Even the parents of ASD children find it hard to describe the differences of the child's sensory characteristics. ASD children themselves struggle to express the hardships they face to others. Hence, even when there are reasons for problem behavior which is seen as peculiar, these reasons are hard for other people to understand. YOUSAY records the preferences or dislikes of the children and how to deal

with them as categorized by sensory characteristics. It also keeps track of daily occurrences as a diary and basic profile of the child. The ability to record entries divided by the eight sensory characteristics and the circumstance facilitates analysis of the children's sensitivity or lack of sensitivity to each sense. Adding positive factors such as the child's likes encourages the caregivers to actively engage with the children. In sum, YOUSAY makes it easier for other people to understand the highly individual sensory characteristics of ASD children, while simply categorizing likes, dislikes, and methods of dealing with dislikes by types of senses. We believe it will act as an information-providing tool to speak for not only the hardships but also the strengths of ASD children.

4.2 Support for families raising ASD children

ASD children living in local communities proceed from infancy to childhood and then to school age, just like children with normal development. When schooling starts, their families want individual consideration for their children and to exchange information with the school. The support book is currently in use to aid families of ASD children. It not only serves as a tool for care-givers to understand the children but also as a way for the family to look back on their raising of the child. However, the volume of paper increases with the child's growth, and preparing summaries requires more hand writing, making it extremely hard to keep up with.

YOUSAY organizes information into sensory characteristics and offers printout features, making it easier to share information or to review the child's growth. The steps taken by the family to deal with difficulties faced by the child are also documented, showing the person who the information is being shared with and the efforts the family has made. This information can be shown to people involved with the child to cope with factors where peculiar behavior might otherwise be mistaken as selfish, attention-seeking, or even due to the family's poor child-raising methods.

In this project, we developed an app called YOUSAY to provide information with a focus on sensory characteristics which families of ASD children are aware of but are often misunderstood by other people. Future issues in order to facilitate use of the app include considering better screen design, controls, number of input characters, sorting screens, integration with other information, and organizing it for use into the future.

5. Conclusion

We developed YOUSAY through working with people of diverse occupations as an app supporting information sharing for families of children with ASD, so that their hopes for the child could be easily conveyed. YOUSAY runs on iPads, and we used FileMaker Pro 14 by FileMaker Inc. for its development. With this app, users can record the child's likes, dislikes, and ways to deal with the dislikes according to separate sensory characteristics. Recording information on an electronic device allows vast amounts of information to be stored and organized, facilitating easier sharing of information on the child.

The families note that looking at records of past data helps them to see how far they have come and to encourage them in their parenting. Many of the families also noted that the app works in a positive way so that the child's special characteristics are not seen simply in negative terms. When the ASD child becomes an adult, at some point the family will turn the tool over to them. We hope to work with the families to further improve YOUSAY and add a sense of playfulness to it that will cheer the child when they receive it in the future.

Acknowledgements

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