

Original Paper

Development of YOUCHART the Information Sharing System for Linking Children with Autism Spectrum Disorder, Their Families and Supporters

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Abstract

The purpose of this study is to develop an application software to facilitate earliest-possible connections between children with Sensory Processing Disorder (SPD), which constantly affects the children's daily lives, in association with Autism Spectrum Disorder (ASD), and their family members and professionals who support them. It is difficult even for family members to understand the distress and difficulties that ASD children with SPD experience in their daily lives. Since 2014, our research team has developed a prototype iPad application YOUSAY (system prototype), which facilitates the sharing of information on sensory characteristics. Nevertheless, YOUSAY alone was not sufficient enough to allow families to play an active role to present information to supporters of ASD children. The opinions aggregated from many test users made us realize that YOUSAY wants (1) the instantaneousness of visually showing the need for support and (2) the handiness of presenting the imbalance of sensory characteristics. In order for this improvement to be successful, therefore, our team has developed a prototype smartphone application named YOUCHART with a new system designed to make it easier for people concerned to instantly and visually assess the feelings of SPD children and their needs as they arise.

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1. Introduction

The characteristics (over- and under-responsivity) of children with Autism Spectrum Disorder (ASD), when they sense stimuli from within and without (henceforth, Sensory Characteristics), have been focused upon ever since a diagnostic criterion for ASD in the 5th Diagnostic and Statistical Manual of Mental Disorders DSM-5 was published in 2013 by the American Psychiatric Association (including sensory issues)^{1,2)}. Likewise in Japan, the supports-for-persons-with-disabilities section of the 2012 Services and Supports for Persons with Disabilities Act included hyper- and hypo-sensitivities in association with ASD as a determining issue to be questioned and considered³⁾.

The unique sensory world in which many children and adults with ASD live has been reported^{4,5)} on television and in newspapers, and those who have grown up with ASD testify⁶⁻⁸⁾ that they were unable to communicate their distress caused by their sensory characteristics in their early years. However, the specific details of how the sensory characteristics of children with ASD interfere with their lives and how the families of children with ASD struggle to maintain relationships with their neighbors in their community are still barely recognized and are often misunderstood by their neighbors^{9,10)}. In addition, it takes a long time for a doctor or specialist to finally diagnose a child as ASD, but mothers, in particular, often have a sense of incongruity with their children from the very earliest stage^{11,12)}.

The Sensory Profile^{13,14)} developed by Winne Dunn, is a world-famous scale for evaluating sensory characteristics. In Japan, Ota and others in 2002 developed the Japanese Sensory Inventory Revised (JSI-R)¹⁵⁾ as an evaluation scale. Also, the Japanese version of Winne Dunn's Sensory Profile, compiled by Tsujii and others in 2015, came out as the Japanese Infant/Toddler Sensory Profile (ITSP)¹⁶⁾, Japanese Sensory Profile (SP)¹⁷⁾, and Japanese Adolescent/Adult Sensory Profile (AASP)¹⁸⁾. This Japanese version is currently used in Japan by clinical psychologists and other professionals who conduct sensory assessments on children with ASD.

Winne Dunn's sensory profile theory^{13,16-18)} illustrates quadrants obtained by intersecting the axes of neurological threshold continua (from high to low thresholds) and of behavior response continua (from passive to active) at right angles: Low Registration, Sensation Seeking, Sensitivity to Stimuli, and Sensation Avoiding. Low Registration is generally viewed as a tendency to be insensitive to stimuli, and responses are often unobserved or delayed^{13,14)}. Sensation Seeking is a state in which active behavior is observed, specific stimuli are sought, and stabilization is considered to be gained by obtaining the stimuli^{13,14)}. Sensitivity to Stimuli, where stimuli are easily sensed, can affect daily life because it usually comes with pain^{13,14)}. Sensation Avoiding, in order to avoid specific disagreeable stimuli, needs to constantly keep the daily environment free of the unpleasant stimuli, so that the procedures of daily life cannot easily be altered^{13,14)}.

The sensory characteristics of ASD children are different from those of children with typical development, and as Sasagase's study¹⁹⁾ showed, the cause of sensory characteristics is derived from physical problems such as physical symptoms. There are many reports on activities and practices that are conscious to sensory characteristics at schools, medical facilities, residential facilities and day-care facilities where professionals are involved. However, it is the family members that spend most of time with children with ASD, and the sensory characteristics of children with ASD are difficult even for their family members to understand, and some families often give up on the sharing of information to supporters in urgent situations. In some cases, it is difficult for family members to connect with supporters even if the family members make a complaint about their children's sensory characteristics at health checkups for 1-and-a-half-year-olds or for 3-year-olds^{11,20)}. It is indeed very hard for family members to give information in a sufficient and orderly fashion immediately as the necessity arises. Paper-based support books require a huge amount of information to be handwritten, which is quite time-consuming to record and update. In addition, as the amount of information increases, it becomes more difficult for the family to find and manage the necessary information on the paper books. What is more, the weight of a support book is heavy and is often so heavy that it is rarely carried around on a daily basis, which makes it impossible to use when a

need arises or in emergencies.

We, the authors of this study, became aware of the necessity of multidisciplinary/multi-professional collaboration in order to provide ongoing support for children with disabilities and their families living in the community; for this mission, we formed a research team named Team Clematis in 2014⁴⁾. Our research team, since 2014, has developed a prototype iPad application YOUSAY^{21,22)} (system prototype), which facilitates the sharing of information on sensory characteristics, through collecting information on the current situation and challenges of children with ASD and their families in a wide range of professions in the community, and considering the importance of the feelings of the families when providing information to supporters. YOUSAY can classify children's sensory characteristics such as "vision", "hearing", "smell", "taste", "touch" and so on in accordance with their likes, dislikes, family members' copings, etc. YOUSAY has enhanced classification functions to facilitate the storage and organization of continuous records by addressing the challenges such as (1) the enormous volume of information, (2) the burdensome frequency in providing information to the supporters, and (3) the importance of such information as those rarely written down. Its features include a search engine, printout function, PDF function and so on, (which paper-based support books were not able to provide). The classification table of sensory characteristics instantly and automatically illustrated by YOUSAY was tested and evaluated favorably by professionals, supporters and family members of children with ASD.

Nevertheless, YOUSAY alone was not sufficient enough to allow families to play an active role to present information to supporters of ASD children with respect to (1) the instantaneousness of visually showing the need for support and (2) the handiness of presenting the imbalance of sensory characteristics. It is the purpose of this study to improve these points. In order for this improvement to be successful, therefore, our team has developed a prototype smartphone application named YOUCHART with a new system designed to make it easier for people concerned to instantly and visually assess the feelings of SPD children and their needs as they arise.

2. Methods

2.1 Preparatory environment and policy for the development of YOUCHART

2.1.1 Multidisciplinary/Multiprofessional research team/organization

As a multidisciplinary/multiprofessional research organization for supporting children with ASD and their families living in the community, our team consisted of seven professionals; four (nursing, school health, psychology, and welfare) with practical experience in working with ASD children and their families, two (information and engineering) with experience in information processing and systems management, and one (design) with experience in creating information communication tools for children with ASD.

2.1.2 Initiatives

After getting approval from the university's ethical review committee, we conducted interviews with 5 family members of ASD children, analyzed the difficulties of the child's sensory characteristics and the family's coping with them from multidisciplinary points of view, and designed an information sharing application. From these interviews, detailed data were gained from five families of children with ASD under the age 18 (as of September-12, 2014) and from the records and notes on one child since birth, and we extracted the descriptions concerning sensory characteristics and examined the content for the development of YOUSAY. We then worked on the development of the YOUCHART with the aim of addressing the issues derived through the development of YOUSAY. A pre-test (April, 2019) was conducted with YOUSAY on family members of ASD children who had participated in interviews before, and one family member of an ASD child and one family member of children with typical development who, among the participants of a voluntary symposium at a conference, had consented to cooperate in the development of YOUSAY.

2.2 Issues from reflections on our previous application software YOUSAY for the development of YOUCHART

Concerning the YOUSAY that we developed earlier, we aggregated opinions from family members of

ASD children and their supporters among the participants of voluntary symposia at conferences, and as we developed YOUCHART we kept ourselves aware of the following issues:

- (1) The terms used in the check points that are designed to facilitate the comprehension of sensory characteristics are difficult for people in general to understand.
- (2) As to the questionnaires meant to grasp the general situation, they let the responders' feelings down when there are many inquiries about things that they "cannot do".
- (3) Support books are quite troublesome if you start utilizing them in the middle stage of a certain age, because doing so invokes so many things that need to be recorded.
- (4) It makes the responders get tired when there are so many questions and evaluation points, which makes it difficult for us to grasp the situation the responders are in.
- (5) It is difficult to determine the differences when the question has four or five levels of response choices.
- (6) Over-sensitivity and under-sensitivity are mixed in sensory characteristics, but their imbalances are difficult to understand.
- (7) The amount of information on sensory characteristics is enormous, so that conveying proper information that is supportive is difficult when asked unexpectedly.
- (8) Even if the imbalances associated with sensory characteristics is revealed, it is still difficult to support the clients.

2.3 Ethical reviews and approvals

We conducted the study, each time as the research progressed, after receiving the necessary ethical reviews and approvals from the ethical review committee of Kawasaki University of Medical Welfare (Approval Numbers : ① 15-015, ② 15-086, ③ 18-111).

3. Results

3.1 Overview of YOUCHART that our team developed

As mentioned above, our team earlier developed YOUSAY, an application software on the iPad, a unique feature of which is its functions that record, classify, search, and print out the family's copings with unpleasantness and difficulties that each of the children feels; including visual, auditory, olfactory, and tactile sensations⁵. For example, YOUSAY is capable of facilitating the sharing of information on a child with sensory characteristics among those who are involved in the child's school. Thus, the burdens shouldered by the families to hand the information over to school staff newly in charge in each school year are greatly reduced.

This time, we developed YOUCHART, a smart chart that focuses on the feelings that ASD children with sensory characteristics sense along the flow of time, which allows their family members to consult with professionals and supporters in a much shorter period of time. The categories on the chart are classified into four check points; "I like very much", "I dislike very much", "I am very sensitive", and "I am unaware", and each of the four check points are subcategorized quarterly so as to be able to grasp the sensations of an ASD child at a certain time with 16 check points in total (Figure 1, Table 1).

3.2 Features of YOUCHART that correspond with eight pre-assigned tasks

There are two main difficulties that family members see as burdensome in providing information on ASD children to professionals: (1) selecting and presenting prior information from the enormous amount of information obtained, and (2) presenting the whole picture of the child's sensory characteristics to professionals in a short and limited period of time. Most of the families cooperate with various surveys and evaluations requested by physicians and other professionals at the time and after the child's diagnosis was determined. However, the thoughts and feelings revealed by the family members to the authors largely included negative feelings and feelings of depression at the time they heard the diagnosis or cooperated in the evaluation survey. Therefore, our team developed YOUCHART with the alleviation of these ordeals in mind.

- (1) The terms and expressions used are not those used in diagnosis or evaluation of a disease or disorder but are carefully selected to be those that are easy for the public in general to understand and are quite

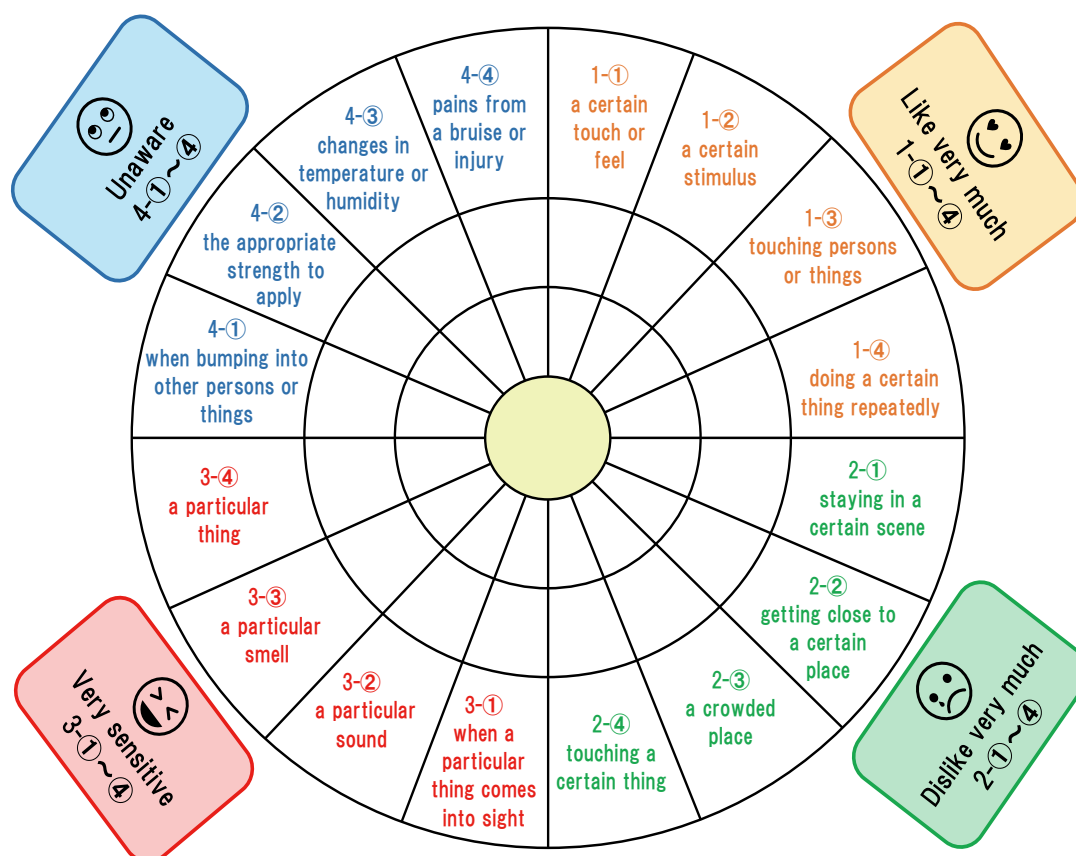


Figure 1 YOUCHART

friendly as regards their feelings.

- (2) Negative expressions such as "cannot do" are dispensed with, because our mission is to support people with sensory characteristics.
- (3) The system can be helpful and useful at any age and the data in progress can be continuously checked and compared at any milestone of the life stage.
- (4) The time needed to read all the 16 check points has been designed to be accomplished in about 2 to 3 minutes, making it less burdensome to work with.
- (5) The 16 check points were derived from the 4 main categories: "I like very much", "I dislike very much", "I am very sensitive", and "I am unaware", which correspond with the diverse nature of sensory characteristics, and are made easier in order to grasp the whole picture with the dark-to-light gradation of colors.
- (6) Each check point consists of 3 choices so as to reduce confusion in answering questionnaires, with the attention of "need to be observed" on the choice of "sometimes in some cases, difficult to judge".
- (7) Each of the 4 main check points: "I like very much", "I dislike very much", "I am very sensitive", and "I am unaware" is subcategorized further into 4 check points with a way of expression that provides more detail with dark-to-light gradation of colors so that the supporters can easily focus on the balance of information they need to check on when they provide that necessary support.
- (8) The dark-to-light gradation of colors as the means of expression for answering makes the "need to be observed" and "need to support" indications much clearer visually so that YOUCHART can serve as a more efficient communication tool with the supporters.

3.3 The composition of YOUCHART

YOUCHART's main categories "I like very much", "I dislike very much", "I am very sensitive", and "I am

Table 1 [Supporting application software for people with SPD] 16 feeling check points

* If you are a parent of a child, please throw yourself into your child's feelings and then answer the following questionnaire.



1. I like very much

1-①	I like a certain sensation so much that I can hardly change it myself.
1-②	I like a certain sensation so much that I can hardly stop it myself.
1-③	I like to keep on touching other persons or things I like regardless of occasions.
1-④	I like to keep on doing a certain thing repeatedly because I like the stimulus very much.



2. I dislike very much

2-①	I avoid staying in a certain scene.
2-②	I avoid getting myself close to a certain place.
2-③	I avoid being in a crowded place.
2-④	I avoid touching a certain thing.



3. I am very sensitive

3-①	I am very sensitive when a certain thing comes into sight.
3-②	I am very sensitive to a certain sound.
3-③	I am very sensitive to a certain smell.
3-④	I am very sensitive when I only touch a certain thing.



4. I am unaware

4-①	I am unaware when I bump into other persons or things.
4-②	I am unaware of appropriate strengths I need to apply.
4-③	I am unaware of changes in temperature and humidity.
4-④	I am unaware of pains when I get a bruise or injury.

※The gradation colors on the double circle illustrates each zone of the feeling check points with regard to sensory sensitivities according to the answers for the questions. The darker the shades of color that there are, the greater the need for support that there will be.

- Not applicable : Null Color
- Frequently or Sometimes Applicable Depending on Occasions / Undistinguishable(Need to be observed) : Thin Color
- Applicable : Thick Color

※The four color zone classifications and the shades of color that are in accord with each of the feeling check points so as to be able to illustrate each individual's need in focus.

1. I like very much ... Orange Zone
2. I dislike very much ... Green Zone
3. I am very sensitive ... Red Zone
4. I am unaware ... Blue Zone

unaware", that go along with the feelings of ASD children with sensory characteristics and each of these categories, is classified into 4 subcategories and is in charge of 16 check points in total.

When responders such as a parent of a child answer the questionnaires, they are expected to follow the direction "If you are a parent of a child, please put yourself into your child's feelings and then answer the following questionnaires" and the like. Thus, the first-person singular "I" in the questionnaire statements is meant to refer to the avatar of the child concerned played by any responders who take care of the child concerned when answering YOUCHART.

- (1) The category "I like very much" is within the range of Sensation Seeking, zoned in the orange color. Its 4 subcategories are ① I like a certain sensation so much that I can hardly change it myself, ② I like a certain sensation so much that I can hardly stop it myself, ③ I like to keep on touching other persons or things I like regardless of the occasion, ④ I like to keep on doing a certain thing repeatedly because I like the stimulus very much.
- (2) The category "I dislike very much" is within the range of Sensation Avoiding zoned in the green color. Its 4 subcategories are ① I avoid staying in a certain scene, ② I avoid getting myself close to a certain place, ③ I avoid being in a crowded place, ④ I avoid touching a certain thing.
- (3) The category "I am very sensitive" is within the range of Sensitivity to Stimuli zoned in the red color. Its 4 subcategories are ① I am very sensitive when a certain thing comes into sight, ② I am very sensitive to a certain sound, ③ I am very sensitive to a certain smell, ④ I am very sensitive when I only touch a certain thing.
- (4) The category "I am unaware" is within the range of Low Registration zoned in the blue color. Its 4 subcategories are ① I am unaware when I bump into other persons or things, ② I am unaware of the appropriate strength I need to apply, ③ I am unaware of changes in temperature and humidity, ④ I am unaware of pains when I get a bruise or injury.

3.4 The function of YOUCHART

3.4.1 Features of YOUCHART categories

- ① The terms and expressions used in the categories on YOUCHART are going along with the feelings of ASD children with sensory characteristics and are easy for non-professionals to understand.
- ② Keeping the easiness and smoothness of answering questionnaires in mind, the order of YOUCHART categories is arranged to be that of "I like very much", "I dislike very much", "I am very sensitive", and "I am unaware".
- ③ The negative expressions such as "cannot" are dispensed with from YOUCHART's 16 check points. This is one of the implemented results of the feedback that came from ASD children's family members and other collaborators who cooperated in our past surveys. They said they were hurt by words such as "cannot", "lack", "abnormal" and the like. Thus, we carefully expelled these kinds of negative expressions from YOUCHART.

3.4.2 The procedures for answering YOUCHART check points

When responding to the 16 check points on YOUCHART, each one has only 3 choices: "applicable", "sometimes in some cases, difficult to judge" or "not applicable". The reason we did not make it a binary selection of "applicable" or "not applicable" is that the choice "sometimes in some cases, difficult to judge" can be the most appropriate choice when, for example, the family members feel unsure about their child, especially about how the child is outside of the home. The answer "sometimes in some cases, difficult to judge" is also quite important data for supporting ASD children; therefore, we classify it as "need to be observed".

3.4.3 The visualization of YOUCHART check points

On YOUCHART, a double-doughnut circle illustrated with the gradation of colors elegantly appears on the screen. Its superiority is that it has no missing parts. In the case of radar charts, they usually illustrate the results with missing parts, which made the family members feel that something was lacking from their child. They said that they were very hurt by the missing parts on a radar chart. For the 16 check points

(including the 3 choices that were explained above), we visualized the 32 points on a double-doughnut circle with the dark-to-light gradation of colors. The darker each color zone is the more support the child needs. This visualization enables one to judge ASD children's needs then and there. On YOUCHART, the dark-to-light gradation of colors is not for diagnosis or assessment but is for the sharing of vital information for supporting ASD children made available on the spot. It is a communication tool that instantly shows the balance of each ASD child's sensory characteristics on one sheet which is shared in real time by professionals.

3.4.4 Time needed to answer YOUCHART check points

The 16 check points on YOUCHART were presented on a single sheet of paper to provide a perspective for time needed to answer all the questionnaires. Usually, detailed questionnaires take a lot of time to answer because sensory characteristics are enormously diverse. Since YOUCHART is not intended to diagnose or evaluate a respondent, answering the 16 check points takes only about 2 minutes for people without sensory characteristics and only about 3 minutes for people with sensory characteristics.

3.5 Case study

One mother of a 17-year-old child with ASD (Case 1) and another mother of a child with typical development (Case 2) responded to the 16 check point color system on a paper version of YOUCHART. From the results, we made out each chart by coloring the necessary areas.

3.5.1 Case 1

The mother of the 17-year-old boy responded to the 16 check points on YOUCHART for the boy's state at his current age 17, at age 14, at age 9, and at age 4, respectively (Figure 2).

Mother's comment:

I was able to check the items on YOUCHART in a short period of time without feeling bad about any of the items. It took me only three to five minutes even if I did a careful review of my child's state in the past while answering. It was good that any negative choices were kept to a minimum. The color system was good for showing the changes in my child's development over time and also how "the current state" of my child changed from kindergarten through high school.

The questionnaires are easy to answer because each answer is limited to a selection from 3 choices. If the choices had been 4 or 5, the nature of the question would have been more subtle and I would have been perplexed when answering. In reality the judgement "applicable" or "not applicable" is what matters, and the choice "unjudgable" is also useful in making me realize that the point "need to be observed" matters. When my child was still very young, it was very difficult for me to make others understand the problems derived from sensory characteristics, but with YOUCHART I think all the difficulties will be cleared away because I can consult with professionals by having them see YOUCHART in real time. Operating YOUCHART on application software will be fantastic, but it was also easy for me to work on a small piece of paper, so I hope both measures for recording and charting will be kept available.

3.5.2 Case 2

The mother of a seven-year-old girl and a ten-year-old boy responded to the 16 check point color system for YOUCHART as it related to their current states (Figure 3).

Mother's comment:

For all YOUCHART check points there were barely "applicable" items with regard to my children, so it took me less than 2 minutes to answer for each of my two children. I think everyone more or less has sensory characteristics, but when the intensity is high it must be very tough to live an everyday life. That was what I thought while I was answering the questionnaires. A friend of mine has a child with ASD, and as much as I know about the child I realized that there were items applicable to the child. Because it uses colors, YOUCHART must come in handy when one needs to consult with professionals and supporters. Answering it takes only a matter of minutes, so you can readily check and become more aware of sensory issues.

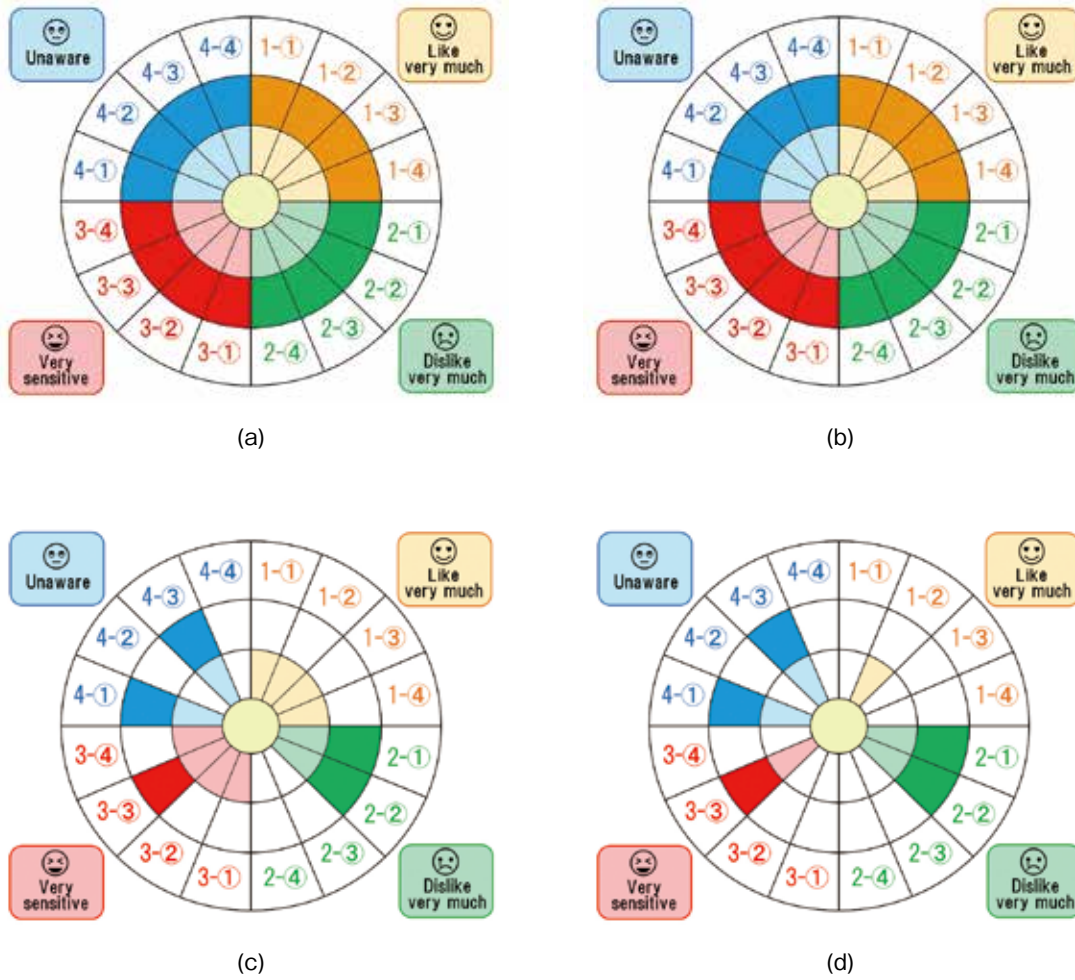


Figure 2 Case 1: ASD child's transition of sensory characteristics
 (a) at age 4, (b) at age 9, (c) at age 14 and (d) at age 17

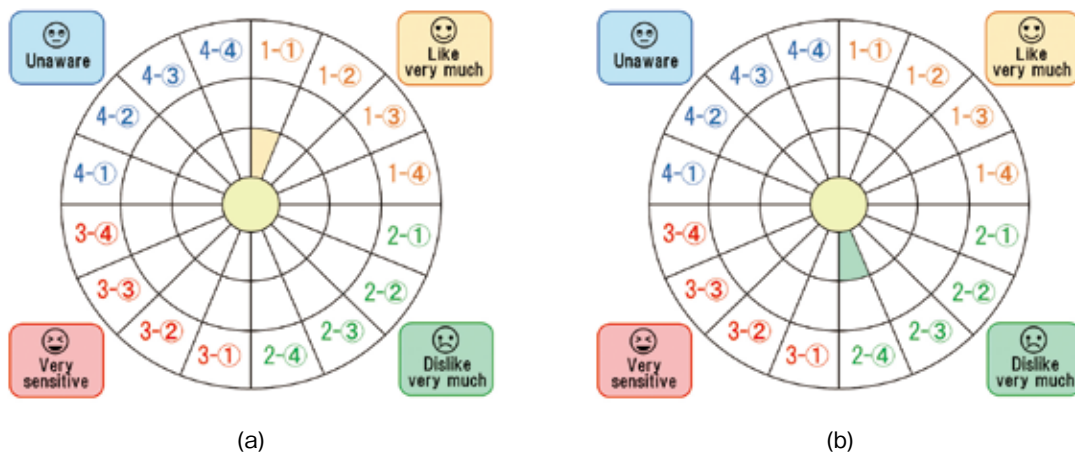


Figure 3 Case 2: Siblings with typical development
 (a) a boy at age 10 and (b) a girl at age 7

4. Discussion

4.1 *Providing and sharing of information on the diverse sensory characteristics*

The authors of this study were often consulted by the family members of children with ASD, and we noticed that there were many cases of latent sensory characteristics. However, it is difficult even for parents to convey the sensory characteristics of their child with ASD to others because of the differences in their own senses from the child's. In addition, it is very difficult for children with ASD to express their painful feelings to others. Therefore, we aimed to develop YOUCHART so that it can illustrate ASD children's feelings as clearly to others as possible.

YOUCHART instantly and efficiently grasps an ASD child's distress from the check points "I dislike very much" and "I am very sensitive", in a way that is compassionate toward the child's feelings. From the check point "I am unaware", YOUCHART provides us deeper understanding of why the people around the child should pay attention to the safety of the child and of why the child frequently gets involved in troubles with others. From the check point "I like very much", YOUCHART lets us know that the stoppage or suspension of a certain stimulus is a huge pain for an ASD Child, and it gives us insights for supporting the child's coping with stimuli seeking. At the same time, since the check point "I like very much" can be understood as the child's strong point, YOUCHART promotes a lively discussion with the supporters about the child's potential.

The interviews with the family members of ASD children revealed that some of them had to struggle both with Sensitivity to Stimuli and Low Registration at the same time, having been in agony over the imbalance^{11,23}. YOUCHART deals with this imbalance of sensory characteristics by visualizing it with the red color zone corresponding with "I am very sensitive" and the blue color zone corresponding with "I am unaware" on the double-doughnut circle; thus, it provides us with the visual grasp of how difficult it is for a family member to cope with the imbalance.

As Sasaki²⁴ stated "It may be that the disabled, because they have disabilities, are the first to become aware of the inconveniences in this world and tell us about them", the as-early-as-possible detection of pains from sensory characteristics and the provision of a "providing environment" for alleviating the pains, will have a huge effect on a child's ongoing life and development. In order to live through adolescence and youth smoothly, children must be provided with the proper care from people around them so that they can adapt themselves to each of life's stages.

4.2 *Support for families of children with ASD*

The 2017 official advice based on the evaluation and results of monitoring on the support for persons with developmental disabilities²⁵ by Japan's Internal Affairs and Communications Ministry specifies "The family is very important for the development of a child, and the more accurately the family understands the child's characteristics and the more willingly the family seeks to receive support, the more likely they are to receive support," and "Failure to adequately promote the family's understanding of a child's characteristics can lead to inadequate support, making it difficult to expand the child's potential and putting the child at risk of acquiring secondary disabilities and compromising the child's future healthy life." YOUSAY^{21,22}, from this point of view, can provide organized information on enormously diverse sensory characteristics, making much lighter the burdens of sharing a vast amount of information among the supporters and family members.

YOUCHART actualized visualization and instantaneous and handy communication between the families of ASD children and professionals concerning what area of support is needed for children's sensory characteristics. In addition, since YOUCHART's check points are not for the purpose of diagnosis or evaluation and the terms used are adopted from common daily expressions, the family members were able to respond to all the questionnaires without feeling any unpleasantness, as the cases 1 and 2 above showed.

In the case of 1, when the mother of an ASD child compared the results of YOUCHART according to the several stages of age as the child grew, the mother noticed, from the shades of color on the results, the change from "applicable" to "sometimes in some cases, difficult to judge" reflected the trail of her own efforts

to cope with the environment. The double-doughnut circle that we contrived, which visualized the check points requiring observation, also made the family's burden easier to understand. This mother's awareness suggested that YOUCHART instantly provided supporters with comparisons of the situations at the many stages in the long process of her child's growth, which in turn made the mother feel encouraged to consult with supporters on her own initiative.

In the case of 2, the mother of siblings with typical development was able to answer the questionnaires without any discomforts just as the mother in the case of 1, suggesting that YOUCHART is not designed specifically for the disabled but is easy for anyone to use.

4.3 Possibilities of YOUCHART

Sensory characteristics are not limited to children with ASD. However, sensory characteristics in childhood are problematic because people around children with ASD do not understand the long-persisting painful experiences or when it is most difficult for them as children to express themselves, as the experiences told by people with ASD when they grew to be adults reveal. The use of YOUCHART, which is designed to be compassionate for a child's difficulty in expressing his or her feelings, should make adults concerned more aware of the difficulties of a child at an earlier stage. When the darker color parts of YOUCHART provoke a discussion among the people concerned, the family members are able to focus on the episodes specific to the sensory characteristics to be conveyed. As a result, the families and supporters can share information in a short period of time, which should reduce the burden on both parties. For example, if the information obtained at the time of the mandatory health examinations for 1-and-a-half-year-olds or for 3-year-olds are shared the families and supporters are able to get hold of the information obtained concerning their children's sensory characteristics in a short period of time. In addition, with YOUCHART, it is possible to grasp the balance in sensory characteristics in a short period of time by, for example, showing which characteristic affects those family members who responded "yes" to the question of whether or not their child has hypersensitivity or hyposensitivity in the survey of "classification of disability support"³⁾. For this purpose, it is important that the YOUCHART application software should be installed on smartphones and then verified by the families of children with ASD and their supporters. On this basis, like the Maternal and Child Health Handbook, YOUCHART can effectively operate from the birth of the child and comes in very handy as a communication tool that encourages the family members to readily consult with supporters when necessary.

5. Conclusion

Our team of multidisciplinary/multiprofessional collaborators developed the application software YOUSAY as a support system for sensory characteristics. We then further developed a prototype called YOUCHART so as to provide earlier and quicker support for strengthening the connection between families of ASD children and their supporters.

In the future, we would like to develop an application software for smartphones, so users will be able to enjoy more convenience and mobility. In order for this to be successful, we need to keep in mind that we should verify the readability of the screen, the easiness of operation, the number of letters needed to be put in, the screen arrangement, the integration of YOUCHART and the categorization chart of sensory characteristics, and the prospects for future developments. We would also like to keep in the back of our minds the possibility for YOUSAY and YOUCHART to evolve into a useful and effective tool for emergencies and disasters.

Conflict of interest

There is no conflict of interest in this study.

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YOUSAY and YOUCHART, the two independent sensory characteristic support systems on application software are patent pending (2019-238602).

References

1. American Psychiatric Association : *Diagnostic and Statistical Manual of mental disorders*, 5th ed, American Psychiatric Publishing, Arlington, 2013.
2. Miyakawa J : DSM-5, revised diagnostic criteria by American Psychiatric Association: Neurodevelopmental disorders, intellectual disabilities, and autism spectrum disorder. *Japanese Journal of the School of Education Sugiyama Jogakuen University*, 7, 65-78, 2014. (In Japanese)
3. Social Welfare and War Victims' Relief Bureau by Ministry of Health, Labour and Welfare : *Manual for examiners for certification of the disability support category under act on the comprehensive support for the daily and social life of persons with disabilities*. https://www.mhlw.go.jp/file/06-Seisakujouhou-12200000-Shakaiengokyokushougaihokenfukushibu/6_5.pdf, 2014. (August 29, 2020)
4. Shapin S : Seeing the spectrum: A new history of autism. *The New Yorker*, January 25, 65-69, 2016.
5. Meg St-Esprit : What is sensory processing disorder?: Children who are deemed 'sensitive' or 'picky' might be struggling with a treatable condition. *The New York Times*, April 17, 2020.
6. Iwanaga R, Fujiie H and Niki-Rinko : *Autism children (second sequel): This is how they are made! Building body for self-support and independence*. Fuukasha, Tokyo, 2008. (In Japanese, translated by the author of this article)
7. Grandin T : Calming effects of deep touch pressure in patients with autistic disorder, college students, and animals. *Journal of Child and Adolescent Psychopharmacology*, 2, 63-72, 1992.
8. Moriguchi N : *Variable Star: The world the autism girl was able to have seen*. Fuukasha, Tokyo, 2004. (In Japanese, translated by the author of this article)
9. Honda H : Neurodevelopmental disorders in adults. *Japanese Journal of Cognitive Neuroscience, Japanese Journal of Clinical Psychiatry*, 19(1), 33-39, 2017. (In Japanese with English abstract)
10. Morito M, Odagiri S, Iwado M, Mikami F, Miyazaki H, Nanba T and Takei Y : Family support with attention to the sensory sensitivities of children with sensory processing disorder associated with autism spectrum disorder. *Kawasaki Medical Welfare Journal*, 27(1), 13-25, 2017. (In Japanese with English abstract)
11. Morito M, Takei Y, Odagiri S, Iwado M, Mikami F, Miyazaki H and Nanba T : Feelings of a mother in reflection on her experience of caring for her child with sensory sensitivities associated with autism spectrum disorder up to 3 years of age. *International Nursing Care Research*, 16(4), 93-103, 2017. (In Japanese with English abstract)
12. Cutler E : *A Thorn in my pocket: Temple Grandin's mother tells the family story*. Future Horizons, Inc. Arlington, Texas, 2004.
13. Dunn W : The impact of sensory processing abilities on the daily lives of young children and their families: A Conceptual model. *Infants & Young Children*, 9(4), 23-35, 1997.
14. Dunn W, Smith Myles B and Orr S : Sensory processing issues associated with asperger syndrome: A preliminary investigation. *The American Journal of Occupational Therapy*, 56(1), 97-102, 2002.
15. Ota A : Reliability study of the Japanese Sensory Inventory Revised. *Japanese Journal of Sensory Integrative*, 10(1), 49-54, 2004. (In Japanese with English abstract)
16. Dunn W : *Infant/Toddler Sensory Profile (ITSP), Japanese edition under the supervision of Tsujii M*. Nihon Bunka Kagakusha, Tokyo, 2015. (In Japanese, translated by the author of this article)
17. Dunn W : *Sensory Profile (SP), Japanese Edition under the supervision of Tsujii M*. Nihon Bunka Kagakusha, Tokyo, 2015. (In Japanese, translated by the author of this article)
18. Brown CE and Dunn W : *Adolescent/Adult Sensory Profile (AASP), Japanese edition under the supervision of Tsujii M*. Nihon Bunka Kagakusha, Tokyo, 2015. (In Japanese, translated by the author of this article)
19. Takahashi S and Masubuchi M : A study of real conditions and support of "hyper-sensitivity and insensibility" of persons with asperger syndrome and high-functioning autism: Needs survey of persons

- with asperger syndrome and high-functioning autism. *Bulletin of Tokyo Gakugei University, Educational Sciences*, 59, 287-310, 2008. (In Japanese with English abstract)
20. Sasamori H, Gokami T, Kuboyama S, Kobayashi M, Hirose Y, Sawada M and Fujii S : Current situation and problems for early detection and early support for children with developmental disability. *Bulletin of the National Institute of Special Needs Education*, 37, 3-15, 2010. (In Japanese with English abstract)
 21. Miyazaki H, Mikami F, Iwado M, Odagiri S, Namba T, Takei Y and Morito M : Development of YOUSAY the information sharing system for families of children with autism spectrum disorder. *Kawasaki Journal of Medical Welfare*, 24(1), 33-42, 2018.
 22. Morito M : Linking persons with sensory characteristics, family members and supporters: Development of information sharing system on information and communication technology by multiprofessional collaboration. *Japanese Association on Intellectual Disability [Support]*, 743, 65(12), 20-23, 2018. (In Japanese, translated by the author of this article)
 23. Morito M, Nanba T, Odagiri S, Iwado M , Miyazaki H, Mikami F and Takei Y : Difficulties children with autism spectrum disorder have in association with sensory processing disorder and their mothers' measures of coping in community life. *Kawasaki Medical Welfare Journal*, 28(2), 389-401, 2019. (In Japanese with English abstract)
 24. Sasaki M : *Can you be grateful to your life?: "The route to a happy life" learned from Erikson's Psychology*. Kodansha, Tokyo, 2012. (In Japanese, translated by the author of this article)
 25. Ministry of Internal Affairs and Communications : *Official advice based on the evaluation and results of monitoring on the support for persons with developmental disabilities*. https://www.soumu.go.jp/main_content/000458761.pdf, 2017. (August 29, 2020)