

Development of a communication book for children with cerebral palsy and communication disorders using the partner assisted scanning method: A pilot study

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ABSTRACT

Background: Cerebral Palsy (CP) is a physical disability impacting movement, posture, and communication. For children with CP and severe communication challenges, methods like Partner Assisted Scanning (PAS) are invaluable. Despite its effectiveness, research on PAS in the context of Thailand is scarce.

Objectives: This study aimed to develop and validate a communication book and related materials for children with CP, utilizing the PAS method. Additionally, the study aimed to analyze communication partners' satisfaction levels with the communication book.

Materials and methods: The study involved two phases. First, four instruments were developed and assessed for content validity: The communication Abilities Assessment, the Communication Partners' Satisfaction Survey, the Communication Book Manual, and the Communication Book. In the second phase, these instruments were tested with three families, evaluating partner satisfaction and addressing encountered issues.

Results: The study demonstrated high content validity of the communication book (overall validity index=0.97) as assessed by specialists. Feedback highlighted concerns about the book's format and the time needed for children to grasp its usage. However, communication partners expressed overall high satisfaction (mean=4.67, SD=0.49).

Conclusion: This pilot study establishes the robust content validity of the communication book developed using the PAS method. Moreover, it underscores high satisfaction levels among communication partners, affirming the potential of the communication book to enhance communication skills in children with CP.

Introduction

Cerebral palsy (CP) is a physical or developmental disorder of movement and balance caused by brain pathologies that appear during the development of the brain either before birth, during birth, or after birth, with many factors occurring together.¹ The incidence of children with CP is generally 1.5-3 children per 1,000 live births.² The Department of Empowerment of Persons with Disabilities, The Ministry of Social Development and Human Security, has reported situational data as of March 31, 2021, analyzed by type of disability. Movement or physical disability was the first for 1,043,192 people, accounting for 49.85% of all disabilities. Of this number, there were 16,128 people from early childhood (0-5 years) to school age (5-14 years), accounting for 1.54 percent of

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the number of people with mobility or physical disabilities.³

Children with CP are at risk for complications and comorbidities such as seizures, speech and language impairment, hearing loss, eating disorders, swallowing problems, visual impairment, psychiatric problems, and malnutrition.^{1, 4-6} Studies of children with CP in Europe have shown that 60% of children with CP have communication difficulties, which can range from mild to severe, affecting their language comprehension and expression.^{7,8} Therefore, they must receive therapy to improve their communication skills.

Communication is the exchange of information and ideas. It is divided into two types: verbal (written or spoken language) and nonverbal (facial expressions, body movement, and the use of pictures or symbols).⁹ Children with CP with movement and communication impairments may not be able to communicate verbally but may be able to communicate non-verbally. As a result, a communication strategy or method with assistive devices may be required.¹⁰

The American Speech-Language-Hearing Association (ASHA) describes augmentative and alternative communication (AAC) as a method of communication used by children and adults who have temporary or permanent communication challenges, limitations on activities and communication engagement, or significant speech and language problems, including speaking and writing.¹¹ These are frequently found among children with physical and motor difficulties, autism, and severe intellectual disabilities.¹² The main goal of AAC is to help people with communication disabilities engage independently in their social environment, as well as to improve their ability to communicate their needs and transfer or share information with others for effective interaction and social etiquette.¹³

In general, AAC can be conveyed using simple gestures or body movements (unaided communication), which includes sign language and body language. The use of aided communication is divided into high-tech devices, which include electrical circuits, computers, and sound generators, and low-tech devices that do not include electrical circuits or computers but are typically made from paper or readily available materials such as communication boards, communication books, pictures, real objects, etc.⁹ According to Kathryn, Light, and McNaughton, the use of AAC can begin in early childhood with parent involvement to improve communication skills in both language comprehension and language expression, as well as access to appropriate education planning for the future.¹⁴

The communication book is a tool of AAC, which is low-tech and used for people who cannot speak or have limited speech capability. These people need to point or look at the book to select the items, images, or symbols that they want to communicate. Communication books are suitable for accessing a large vocabulary and can employ various communication access techniques.¹⁵ They also help to expand the vocabulary and knowledge of sentence structure, reduce irritating behavior, and increase role-switching with the interlocutor.¹⁶ Direct and indirect

selection and Partner Assisted Scanning (PAS) are methods for obtaining communications through communication books. A systematic search may be performed by utilizing their eyes, buttons, or switches for children with CP who cannot choose, point, press, or type independently due to restrictions in their motor movements and the use of their fingers.⁹ PAS is an effective communication approach for those with limitations since it involves communication partners such as parents, caregivers, teachers, or therapists to assist in communication.¹⁷ A systematic search is conducted by the communication partner by pointing to and reading aloud from an ordered list. Moreover, the communication partner does a methodical search by pointing to and reading aloud a list of sequences while simultaneously employing visual and auditory scanning.¹⁸ These systematic sequencing methods can be applied to searches using group-item scanning, which is the most efficient way to search for ordered items in column-row scanning.⁹

For these reasons, researchers working as speech and language pathologists regularly observe that children with CP who have physical and motor deficits in addition to significant communication problems have communication learning limits. They are unable to speak or express their needs. Subsequently, children's communication can be misunderstood by parents, and children can become easily frustrated as a result. Parents frequently use short words or sentences while speaking to their children, and they often rely on a limited range of communication functions or provide choices for the children. Due to their limitations, parents lack the necessary knowledge to help their children communicate efficiently, and children must be rehabilitated by enrolling in a speech training program to correct their speech and boost language and communication development. Therefore, using AAC as part of the treatment is essential. Currently, in Thailand, AAC systems are not widely known or used because SLPs may have prejudices or a lack of understanding due to a lack of training and expertise with AAC systems. Seventy-eight percent of Thai SLPs taught children with nonverbal communication to use gesture communication.¹⁹ There are few studies involving communication books and children with CP who can access tools or devices by pointing or selecting pictures directly. There has also been no study of communication books among children with CP who cannot point or select pictures independently but have sufficient vocabulary for basic communication. As a result, the researcher is interested in establishing and developing a communication book for children with CP who have communication disorders by using the PAS. By establishing and developing an easy-to-use and low-cost communication book, as well as an instruction manual on how to utilize the communication book with PAS, it can be used by parents, caregivers, and multidisciplinary teams to treat communication problems in children with CP.

Materials and methods

This research is an experimental study with a one-group pre-and post-test design. The participants in this

study were three children with CP aged 1-15 years with communication difficulties and three communication partners (parents or caregivers) who were receiving rehabilitation services in augmentative and alternative communication clinics at Rajanagarindra Institute of Child Development, Mae Rim District, Chiang Mai Province.

Inclusion criteria for children with CP

1. Children with CP aged 1-15 years with communication disabilities were diagnosed by a doctor, and the doctor ordered the use of augmentative and alternative communication methods.
2. Having developmental assessment results from the Thai Developmental Skills Inventory for Children from Birth to Five Years (TDSI),²⁰ which was assessed by nurses in terms of gross motor and fine motor skills, which found that the child has a delay in development or has physical limitations regarding movements, an inability to walk, limitations in the use of fingers to pick up or point objects, or an inability to help themselves in daily activities, and thereby requires assistance from parents or caregivers.
3. Having developmental assessment results from the Thai Developmental Skills Inventory for Children from Birth to Five Years (TDSI),²⁰ which was assessed by nurses in terms of expressive language and found to be late in childhood, not speaking meaningful words or speaking meaningful words with great difficulty, and in the receptive aspect, the child can understand simple commands and questions and can answer yes or no questions by making a blinking signal or making a refusal or acceptance movement.
4. Having clear vision or wearing visual aids to see clearly, such as glasses in the case of short or long-sightedness, according to a review of their history file.
5. Having hearing within the normal range of less than or equal to 25 decibels or wearing hearing aids that allow for clear hearing, such as wearing hearing aids during testing listed in their profile, and currently responding to commands at a conversation-level volume.
6. Able to understand and use Thai as their primary language and respond by nodding, blinking, smiling, or moving any part of their body.

Inclusion criteria for communication partners

1. Use of Thai as the primary language of communication.
2. Be able to read and write Thai well.
3. Being a parent or caregiver caring for children with CP for at least one year and mainly living with the child.
4. Be a parent or caregiver who can understand and interpret the communication of children in the initial stages, such as if the child accepts or rejects an object by making throat noises or moving any part of his or her body when it is handed to them.
5. Be a parent or caregiver who can communicate, interact, or switch roles with the child.

Exclusion Criteria

Children with CP with diseases that affect movement for communication, such as children with comorbidities e.g., severe intellectual disabilities, seizures that cannot be controlled with medication, etc.

Research instruments

1. An assessment of the communication abilities of children with CP using the PAS method.

There are 10 items in the assessment form that utilize a 3-point Likert rating scale, which includes options for high, moderate, and low ratings.²¹ This scale is used to assess the difficulties experienced by the communication partners as follows:

- A score of 1 means that the child cannot communicate with a communication book using the PAS method.
- A score of 2 means that the child can communicate with a communication book using the PAS method to help with some needs or that takes effort to understand, such as guessing from previous experiences.
- A score of 3 means that the child can fully communicate with a communication book using the PAS method to identify needs immediately.

2. An evaluation form for the communication partner's satisfaction in using the communication book with the PAS method.

There are 15 items in this assessment form, which measures satisfaction in five aspects: format, usability, content, reducing frustration or negative behavior, and the communication partner's understanding of children's needs. This assessment employs a 5-point Likert rating scale, i.e., very dissatisfied, somewhat dissatisfied, neither dissatisfied nor satisfied, somewhat satisfied, and very satisfied.²¹

3. Manual for using the communication book for children with CP and communication disorders by applying the PAS method (Appendix 1).

The researcher studied the theory, documentation, and research related to the creation and design of a communication book manual for children with CP such as Children's Aided Language Tools (CHAT-Now)²¹ and Pragmatic Organization Dynamic Display (PODD).²² Therefore, Defining the contents of the manual, providing detailed information on the primary information of the communication book, its components, the details in the communication books, and how to use the communications book in line with the terms, images, patterns, navigation, and command bars, as the researcher designed and reviewed the literature.

4. Communication book (Appendix 2).

A hardcover folder with two holes inserted and an 80-micron hard laminate display page, A4 size, contains pictures of the PCS system symbols, including appropriate and necessary vocabulary for children with CP and their parents to use for communication in daily life, both the core vocabulary and fringe vocabulary.^{9,22-24} The researcher

divided the words into 20 main and sub-categories: 1) Main page, 2) Categories lists, 3) Help, 4) Feelings, 5) Likes, 6) Dislikes, 7) the Body, 8) Questions, 9) People, 10) Verbs, 11) Activities, 12) Places, 13) Clothing, 14) Things, 15) Eating, 16) Transportation, 17) Animals, 18) Days and time, 19) Descriptions, and 20) Toilets, which can be searched using a vertical search pattern and navigation links to various categories with a number system in conjunction with the Thai alphabet.

Research methods

The research methods can be separated into two phases:

Phase 1. Development of the tools, including four instruments.

First, the researcher developed four instruments: 1) an assessment of the communication abilities of children with CP using the PAS method, 2) an evaluation form for the satisfaction of the communication partners regarding the use of the communication book with the PAS method, 3) a manual for using the communication book for children with CP and communication disorders by applying the PAS method, and 4) a communication book for children with CP and communication disorders that uses the PAS method. These instruments were designed based on a thorough literature review utilizing the theoretical principles of augmentative and alternative communication, with a particular focus on the PAS method theory. After the development of the four instruments, the researcher sent them to five experts specializing in the field of children with CP and AAC to check the content validity by calculating the Index of Item-Objective Congruence (IOC). After receiving suggestions from experts, the researcher used them to improve the content of the instruments. It was considered that an $IOC > 0.5$ would pass the criteria.²¹

Phase 2. Trial of the tools with three families and examination of the satisfaction level of the communication partners using the communication book.

After the expert evaluation and the revision determined that the content validity test was completed, the researcher selected three families who passed the inclusion criteria for the research from the AAC clinic, Rajanagarindra Institute of Child Development,

Department of Mental Health, Ministry of Public Health. They were selected from the order in which they volunteered for research projects. The researcher made an appointment to clarify the details of the research project, including using all four research tools with the communication partners of the children with CP individually for 3 hours per family, one family per day, totaling three days. A lecture and demonstration were used in this clarification by the researcher, who demonstrated to the communication partners how to point and read the symbols for the children to see and hear. When searching for the symbol that the child wants to communicate with, the communication partner will wait for the child to show a response with a movement within limits, such as smiling, blinking, or partial body movements.^{17,18} After finishing the lecture session, the researcher asked the communication partners to check the suitability of using a communication book and supplemental materials by asking about the topic from the communication partners' satisfaction assessment form and to provide suggestions for improvement. After providing suggestions and improvements, the researcher distributed the communication partners' satisfaction assessment form for the use of the communication book using the PAS method to the communication partners of the experimental group to assess their satisfaction with the use of the experimental communication book and conduct an analysis of the data.

Results

Phase 1: Content validity

According to the examined IOC, each item of the content validity test passed the criteria, with the results shown in Table 1.

Phase 2. Trial of the tools with three families and examination of the satisfaction level of the communication partners using the communication book.

After the try-out for 3 hours per family, the suggestions were received from all three families, as displayed in Table 2, and the satisfaction levels of the three communication partners in using the communication book for children with CP and communication disorders by applying the PAS method are displayed in Table 3.

Table 1 Content validity of the instruments.

Content Validity			
No.	Tools	IOC	Result
1	Assessment of the communication abilities of children with CP by using the PAS method	0.99	Passed
2	Evaluation form for the satisfaction of the communication partner in the use of the communication book employing the PAS method	0.95	Passed
3	Manual for using the communication book for children with CP and communication disorders by applying the PAS method	0.97	Passed
4	Communication book for children with CP and communication disorders using the PAS method	0.98	Passed
Overall score		0.97	Passed

Table 2 Suggestions from the three users in the trial phase.

Consideration list	Suggestion	Improvement
1. Format of the communication book	<ul style="list-style-type: none"> Change the format. 	<ul style="list-style-type: none"> The format was changed from a desk-calendar communication book to a folder communication book for easy portability and repair if damaged.
2. Content	<ul style="list-style-type: none"> Some categories may not be used because they have not been taught to children. 	<ul style="list-style-type: none"> The content was kept the same because it is the vocabulary that is necessary for their daily life in the future.
3. Size	<ul style="list-style-type: none"> Use A4-sized communication books so that the children and communication partners can see clearly. 	<ul style="list-style-type: none"> The size was adjusted according to the suggestion.
4. Symbols	<ul style="list-style-type: none"> There may be some symbols that children need time to learn. 	<ul style="list-style-type: none"> The symbols were kept the same so that children can learn these symbols in the future.
5. Usability	<ul style="list-style-type: none"> Some of the samples may not be understood with regard to their usage. 	<ul style="list-style-type: none"> The researcher emphasized that parents should use the communication book in every situation that occurs in daily life and that the children learn all of the content.
6. The manual for using the communication book for children with CP and communication disorders by applying the PAS method.	<ul style="list-style-type: none"> No problems were found in its usage. 	n/a
7. The assessment of the communication abilities of children with CP by applying the PAS method.	<ul style="list-style-type: none"> No problems were found in its usage. 	n/a
8. The evaluation form for the satisfaction of the communication partners in the use of the communication book with the PAS method.	<ul style="list-style-type: none"> No problems were found in its usage. 	n/a

Table 3 Satisfaction of the three communication partners in using the communication book for children with CP and communication disorders by applying the PAS method.

Aspect	List	Mean	SD	Level
1	Format	4.67	0.19	Highest
2	Usability	4.56	0.13	Highest
3	Content	4.80	0.28	Highest
4	Reduction of frustration or negative behavior	4.33	0.47	High
5	Communication partner's understanding of children's needs	4.67	0.28	Highest
Overall		4.67	0.28	Highest

Discussion

Phase 1. Development of tools, including four instruments.

In the content validity test by five experts, passing the criteria required a score of 0.5,²⁵ as shown in Table 1. Thus, when considering the content validity of all the instruments overall, it was found that all of them passed the criteria in terms of their content validity due to the researcher's review of the related literature and theories.

Furthermore, the researcher interviewed communication partners about the words that they used with their children with CP in daily life before setting the contents, as the researcher reviewed the literature such as principles of communication book design,^{15,16,26} word selection,^{9,26} the PAS method,¹⁷ the Communication Matrix,²⁷ the Pragmatic Profile for People who use AAC²⁸, communication books as Children's Aided Language Tools (CHAT-Now),²² Pragmatic

Organization Dynamic Display (PODD),²³ and other relevant research studies. The researcher also asked for opinions about the vocabulary used in daily life from the parents of children with CP before determining the content of the research tools.

For the information that the experts recommended regarding corrections, in instrument 1, the experts recommended adding the disability characteristics of children with CP and adjusting the method of answering the question "What methods do children use to communicate?" to be optional, as well as adding a description of how to communicate with them. In instrument 2, the experts recommended changing the word "beautiful" to the phrase "clarity and beauty" and adjusting the category page or what to study first to make it easier to navigate links to other pages and to be consistent throughout the book. In instrument 3, the experts suggested adjusting words such as "sub-item" page to "sub-category-item" page, adjusting the details of various components in the manual for improved clarity, and adding illustrations to explain the additional information that will help guide users who are parents or caregivers to act as search assistants more clearly and allow them to understand how to use the communication book more easily. In instrument 4, the experts recommended adapting the symbols to be more contextual and culturally relevant to make them easier to use, such as changing the sign for the word "no" from the circle with diagonal slash symbol to a cross symbol because it may be misunderstood that it is forbidden. After the researcher corrected all of the data according to the experts' recommendations, the first set of the four tools was obtained, consistent with the content.

Phase 2. Trial of the tools with three families and examination of the satisfaction level of the communication partners when using the communication book.

After the content validity review by experts, the researcher conducted trials involving three children with CP and their communication partners (Table 2). As a result of this phase, the sample groups proposed several improvements. They recommended changing the communication book format from a desk calendar style to a more portable and repairable folder format. Additionally, they suggested using a larger A4-sized communication notebook to ensure clear visibility of words and symbols for both children and communication partners. At first, some of the samples' usage may not be easily understood. For instance, communication partners may initially struggle to understand how to use the communication book, the PAS method, and the suitable duration and timing for their communication book. Therefore, the researcher emphasized that parents use the communication book in every situation in daily life along with reading the manual for the children to learn it well. Moreover, allow parents to repeat the PAS process to see if they can do it correctly until they can do it themselves through explanations and demonstrations.^{29,30} Due to the diverse backgrounds of the families participating in this research, it is crucial that apart from a more profound comprehension of cultures

and their connections to AAC, the researcher must acquire a heightened sensitivity to the cultural factors that may impact their approaches and suggestions. As a result, families were encouraged to participate in lectures and practice sessions, fostering a shared understanding between researchers and communication partners.³¹ The researcher also asked the communication partners to complete an evaluation form for their satisfaction levels with using the communication book with the PAS method. The satisfaction of the three communication partners in using the communication book for children with CP and communication disorders by applying the PAS method (Table 3) was found to have the highest overall satisfaction level (mean=4.67, SD=0.49).

The researcher developed a tool for communication books in the form of an A4 hardcover folder with display pages consisting of 20 categories of symbolic images. There are links from the main page to different categories to support talking about the daily needs of children with CP. Scope stated that a communication book is suitable for people who cannot speak or have limited communication abilities. The communication book can provide a large vocabulary, and thus, it is suitable for discussing the needs of children with CP in daily life.¹⁵ This corresponds to the principles of communication book development that the researcher has reviewed in the literature. Inside the communication book, there are clearly colored symbols contrasting with the white background, and the large and clear symbols also have words above them to stimulate communication through visual means and listening. Beukelman and Mirenda reported that the Picture Communication Symbols (PCS) system is easy to understand and can be used with various people.⁹ Fanourgiakis also reported that the development of communication books should take into account the number and size of the symbols so that they are suitable for use, the selection of words in the essential vocabulary category, and the needs of that group of people, which is consistent with the researcher having parents help determine the vocabulary that is used frequently with children to include the vocabulary that meets the users' needs and is suitable for continued use.²⁶ In addition, both the vocabulary and symbols are appropriate for the Thai cultural context,²⁴ making it easy for children and communication partners to apply them.

Accessing communication books by children with CP through indirect methods or the PAS method is consistent with Beukelman and Mirenda, who stated that this method is suitable for children with CP or children who cannot select communication lists by themselves.⁹ Therefore, an assistant to search for symbols and pictures used in communication is required. Also, Bayldon and Clendon¹⁷ and Burkhart and Porter¹⁸ describe that the PAS method can be used for people with communication and movement disorders. The communication partner will help to point and read the symbols for the children to see and hear. When searching for the symbol that the children want to communicate, they will show a response with movements within their limits, such as smiling, blinking,

or partial body movements. The PAS method, using visual and auditory content, will help children learn to recognize the symbols and understand more linguistic concepts.

Limitations

Only the results of the tool development process and the communication book trial were included in this research. The trial period in the second phase was relatively short. Therefore, future research should consider extending the trial period to assess the tool's effectiveness more comprehensively.

Conclusion

In the pilot study, it can be inferred that the development of the communication book using the PAS method demonstrated a strong level of content validity, and the communication partners were satisfied with the communication book using the PAS method. However, they suggested changing the communication book's format and size to make it easier to use. Thus, the modified communication book can potentially be used to enhance the communication skills of children with CP in the next phase of the research concerning the efficacy of this communication book using the PAS method.

Conflict of interest

The authors declare no conflict of interest regarding the publication of this paper.

Ethics approval

This research gained ethical approval from the Suanprung Psychiatric Hospital, Chiang Mai (SPH.IRB 004/2564 SCs_ful) for research involving human participants. All samples and participants received all of the necessary information related to the research and informed written consent was obtained before enrolling them in the study.

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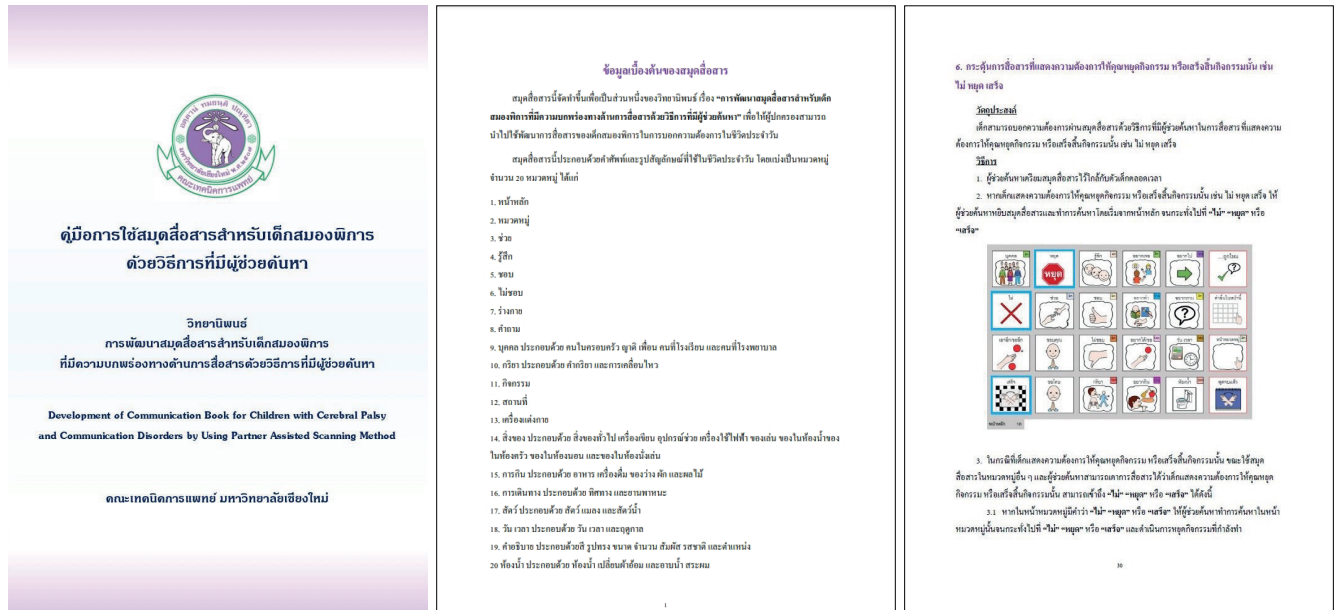
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Appendix

Appendix 1 Example of a manual for using the communication book for children with CP and communication disorders by employing the PAS method.



Appendix 2 Example of the communication book.

