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ORIGINAL ARTICLE

An access technology delivery protocol for children with severe and multiple disabilities: A case demonstration

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Abstract

Objective: This study applied response efficiency theory to create the Access Technology Delivery Protocol (ATDP), a child and family-centred collaborative approach to the implementation of access technologies.
Methods: We conducted a descriptive, mixed methods case study to demonstrate the ATDP method with a 12-year-old boy with no reliable means of access to an external device. Evaluations of response efficiency, satisfaction, goal attainment, technology use and participation were made after 8 and 16 weeks of training with a custom smile-based access technology.
Results: At the 16 week mark, the new access technology offered better response quality; teacher satisfaction was high; average technology usage was 3–4 times per week for up to 1 h each time; switch sensitivity and specificity reached 78% and 64%, respectively, and participation scores increased by 38%.
Conclusion: This case supports further development and testing of the ATDP with additional children with multiple or severe disabilities.

Keywords

Access technology, communication, provision, service delivery, assessment, assistive technology

History

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Introduction

In Canada, more than half a million children and youth under the age of 20 have a disability [1]. Assistive devices have the potential to greatly enhance their lives by increasing their participation in daily activities [2]. However, despite this potential, many assistive technologies are abandoned within the first few months of use [3]. The key to mitigating abandonment may lie in the assessment process, which has been described as the most influential and consequential phase in the provision of assistive technology (AT) [4]. Currently, there is a lack of standardization in the methods used to assess and deliver assistive technologies [4–6]. If research regarding key characteristics for the provision of AT cannot be translated into a method that supports practice and policy, its ability to improve health care systems will remain unrealized [5].

AT prescription

Assistive technology can be defined as any item, piece of equipment or system that is used to increase, maintain or improve the functional capabilities of individuals with disabilities [7]. Prescribing AT has been described as an intrinsically difficult procedure that is prone to failure [4], and the current prescription process criticized as 'fundamentally flawed' [3]. Population statistics suggest that the rate of abandonment for optional AT devices can be as high as 30% [3, 8]. These outcomes are generally the result of user dissatisfaction with an inappropriate technology [8] resulting from an ineffective AT assessment [3].

Many different types of models and instruments for AT assessments have been devised in an attempt to provide better and more appropriate services. However, there is a lack of standardization across the field [3, 5, 6]. This is especially true when working with individuals with multiple and/or profound disabilities. There is consensus in the literature that the current assessment instruments are generally inadequate for this population [3]. Even those instruments based on the most well-accepted models (e.g. Matching Person Theory) have been challenging to incorporate into rehabilitation practice [6], particularly with individuals who have severe and multiple disabilities [3].

A common theme throughout the literature is the need for assessments to focus on characteristics specific to an individual, the tasks they wish to perform and the environment (including caregivers) in which they will be performing them. Other important success factors for AT provision include: consideration of individual or family goals, consideration of family support systems, sensitivity to cultural issues, a multi-disciplinary assessment team, adequate follow-up, suitable technological features and sufficient information regarding past medical and/or educational history [1, 3, 9]. For individuals with multiple and severe disabilities, in particular, Hoppestad recommends that the assessment process be flexible

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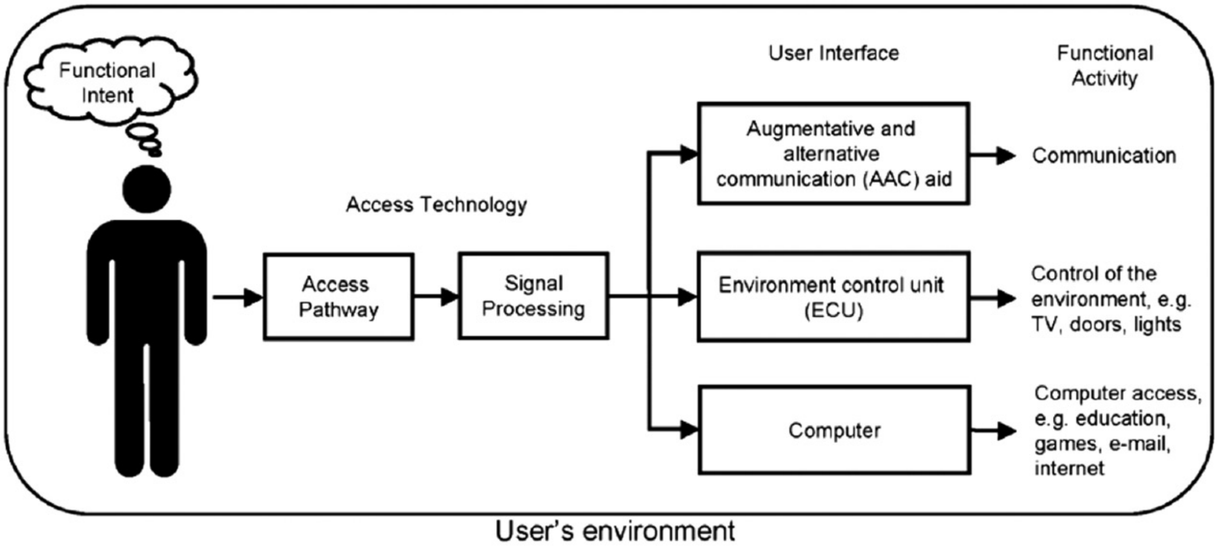

Figure 1. Components of an access solution within the users' environment [11].

and highly individualized, including both formal and observational testing [3]. Assessments for these individuals cannot rely on a single test or testing instrument, but must include information from multiple sources [3]. An assessment method should incorporate as many of these recommendations as possible in order to promote successful AT provision.

Access technologies

An access technology is a particular type of AT that translates the intentions of a user with severe physical impairments into functional interactions [10]. As seen in Figure 1, an access technology is the portion of a larger access solution consisting of an access pathway and a signal-processing unit [10]. Access pathways, when paired with the appropriate user interface, can power anything from wheelchairs to lights and televisions to communication devices [10]. The access pathway, commonly known as a switch, comprises the actual sensors or input devices by which an expression of functional intent is transduced into an electrical signal [10]. The signal-processing unit analyses the input signal from the pathway and generates a corresponding control signal that drives the user interface [10]. The success of all components in an access solution hinges on identifying an access technology that is well-suited to the individual.

Response efficiency

Johnston and Evans [11] contended that a better contextual fit can be achieved between user and intended usage, and the likelihood of device abandonment diminished, through an application of response efficiency in the development and implementation of AT. The concept of response efficiency is based on the matching theory from applied behavioural analysis [11, 12]. The theory states that when individuals have the opportunity to choose between two or more functionally equivalent alternatives, they will select the option that they perceive as most efficient [11]. Four factors have been identified as having significant influence on an individual's interpretation of response efficiency [11]:

(1) Response effort – The physical and cognitive effort required to produce a response.
(2) Rate of reinforcement – The rate at which the individual receives a response, e.g. every time they use the technology, every other time, every third time, etc.
(3) Immediacy of reinforcement – The delay, if any, between using the technology and observing the desired result.
(4) Quality of reinforcement – How closely the reinforcement coincides with the user's expectations, e.g. exact match, close match or complete mismatch.

Although each of these factors contributes to the overall perception of efficiency, their relative weighting can vary from individual to individual, and within individuals over time, depending, in part, on the device or the environment [12, 13].

Assessment development

The application of response efficiency concepts to the assessment process that could result in better contextual fit between an intervention and each of the following: characteristics of the person for whom the intervention was developed, characteristics of the individuals who will implement the plan, and features of the environment within which the intervention will be implemented [11, 14]. Additionally, devices that are compatible with the individual and his/her environment will likely have good overall response efficiency. Therefore, we contend that the primary focus in developing a method of assessment for access technologies ought to be on the collection of information pertinent to optimizing each of the four factors influencing response efficiency. This information should be gathered from the user and the caregiver, as both perceptions are equally critical in obtaining good contextual fit. In addition to the contextual fit, literature also suggests that a multi-disciplinary team, flexibility and follow-up are critical to access technology prescription for individuals with severe disabilities [1, 3].

Thus, the purpose of our research was to create and evaluate an access technology-specific assessment process based on the concept of response efficiency. The intention is that such an assessment would eventually inform the identification and development of individualized access pathways.

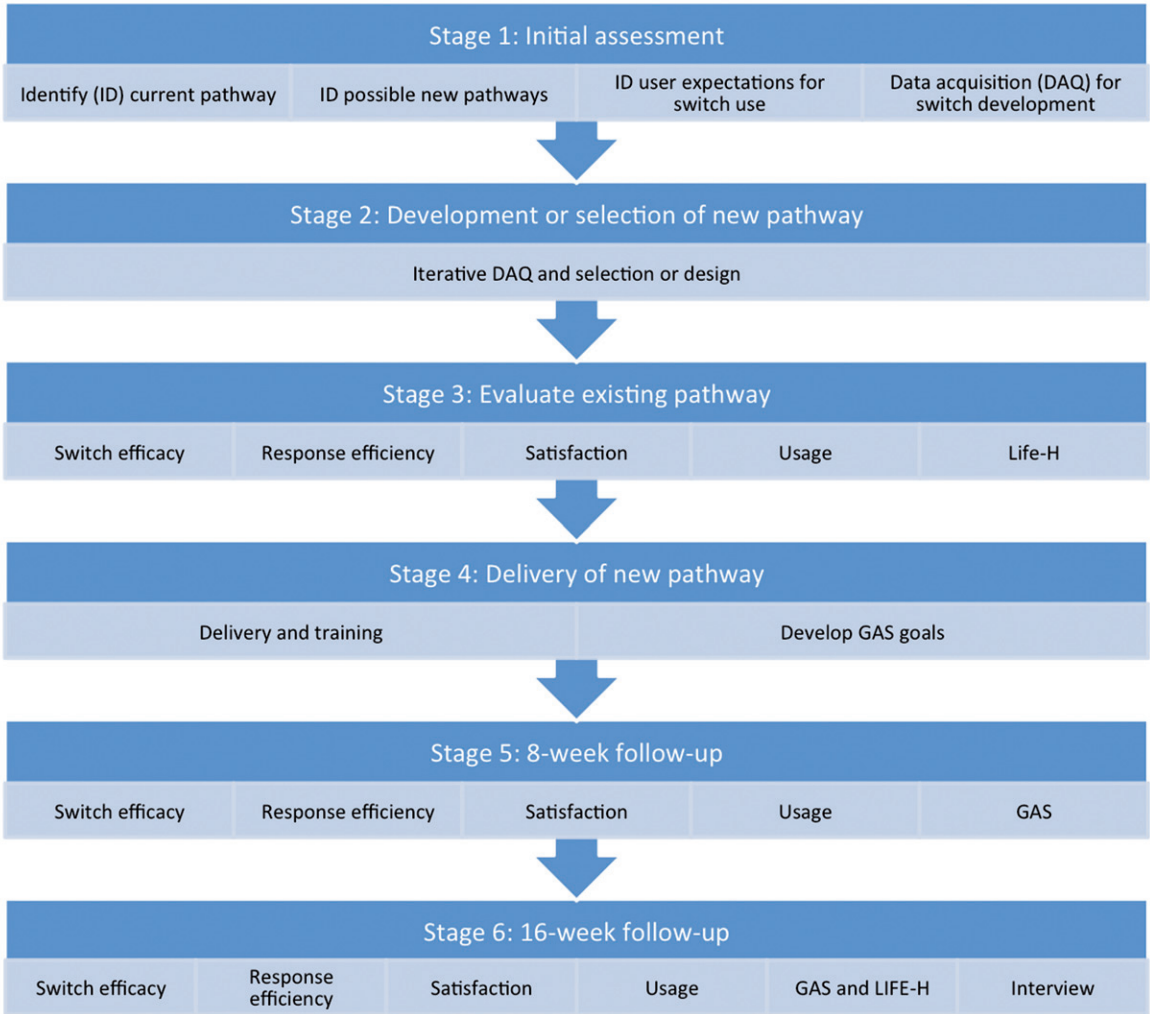

Figure 2. Outline of the access technology delivery protocol (ATDP).

Objectives

The objectives of this study were to:

(1) Create a response efficiency-theoretic assessment process that will inform the identification and development of individualized access pathways.
(2) Apply this assessment to a single subject case study and subsequently compare the response efficiency with the resultant technology to that of the previous method of access.
(3) Describe the appropriateness (according to ISO 9241-9) of the access technology.
(4) Gauge the usage, goal attainment and participation outcomes associated with the introduction of a new access technology.

Methods

The proposed access technology delivery protocol

We designed a novel access technology delivery protocol (ATDP) to provide a response-efficient access technology. The proposed assessment and follow-up procedure are outlined in Figure 2. The six-stage process was developed as a flexible and generic method for incorporating the concept of response efficiency, as well as the measurement of outcomes associated with the pathway. The actual assessment comprises Stage 1, while iterative and collaborative switch development occurs in Stage 2. The other four stages are evaluation procedures. In the 16 weeks after the delivery of the new technology, the user gets trained with their new switch in the context of the personally identified activities. The 16-week time frame was chosen because it exceeds the 3-month period during which many assistive technologies are abandoned [3].

The ATDP requires an inter-professional collaboration between a clinician (speech language pathologist or occupational therapist) and clinical engineer as project team members. It also provides critical opportunities to fully engage teachers, educational assistants, parents, other caregivers, and school- or children treatment centre-based therapist teams.

Assessment (Stage 1)

In order to maintain the content flexibility suggested by the literature, the assessment stage is conducted primarily through an interview process, with additional information obtained through a Client Information Questionnaire [15]. The interview portion does not contain a specific question set, but is focused instead on obtaining as much information as possible about the user and caregivers and what they would perceive as a response efficient solution. This includes details regarding the current access pathway, reasons for dissatisfaction, expectations for how and where the new access technology will be used, and potential access sites that require minimal user effort. This interview is conducted with the user, and as many of their communication partners (i.e. caregivers, teachers and clinicians) as possible. These individuals are most familiar with the user's needs and abilities, as well as their future desires and potential, and will eventually interact with the technology. The Client Information Questionnaire collects basic information regarding the physical function, cognition, sensory acuity, motor skills and communication skills of the individual, and identifies the primary and secondary caregivers.

Development/selection and delivery of a new pathway (Stages 2 and 4)

Information gathered in the initial assessment informs the decision about potential access pathways for the individual. The preferred pathway is chosen based on consensus from the family, caregivers, teacher, clinicians and the engineer. Existing switches for this pathway, where applicable, are presented to the individual and caregivers for their review and approval before moving forward. Where no suitable technology is available, concept suggestions for an appropriate switch are presented to the caregivers, individual and clinicians for their approval. In this case, once there is agreement as to the most suitable concept, the clinical engineer proceeds to develop the switch. This process may involve multiple data collection sessions with the individual before the optimal set-up is obtained. The final switch (selected or developed) is delivered to the individual as soon as it is approved and completed. Basic training on switch set-up and use is provided to the user and caregivers over one to three visits at the time of delivery, depending on the number of people in the child's circle of care who require training and the complexity of the set-up (e.g. positioning, calibration).

Evaluation procedures (Stages 3, 5 and 6)

One of the criticisms of many assistive technology selection tools and practices is the lack of outcome data [6]. To evaluate the selected/developed access technology, we assembled a collection of qualitative and quantitative measures to assess the four factors influencing response efficiency as well as efficacy and satisfaction. The evaluations, starting with measurement of response efficiency, are described below and are administered for both the current means of access (if one is in place) and novel means of access to allow direct comparison. For each of evaluation stages 3, 5 and 6, the user is seen by the project team three times over a 2-week period for switch efficacy measures and data are pooled across sessions for analyses.

Response effort

A Borg Scale, from 'ISO 9241-9 Requirements for non-keyboard input devices', is used to assess the perceived effort required to use the access pathway for both the user and the caregiver. This version of the Borg Scale has 12 points, within a scale that ranges from 0 to 10, representing the percentage of maximum muscular strength that a given activity requires [16]. A representation of the scale is shown in Table I, with descriptors in brackets representing whole-body effort. As the scale descriptors are general, we were able to use the scale in an unmodified form to assess perceived cognitive effort required for a given task or activity. In circumstances where the user is unable to rate his or her own effort, e.g. due to cognitive difficulty, a caregiver is asked to give his or her best estimate of the user's effort.

Table I. ISO 9241-9 version of Borg Scale [16].

Points	Effort representation
10	Very, very strong (almost max.)
9	
8	
7	Very Strong
6	
5	Strong (heavy)
4	Somewhat strong
3	Moderate
2	Weak (light)
1	Very weak
0.5	Very, very weak (just noticeable)
0	Nothing at all

For users who are already working with a switch, but are seeking a new technology, a second measure of response effort is deployed. The user is asked to play a computer game where they are required to activate their switch as many times as possible within a 30-s period. They are then given a 1-min break, and asked to perform the same task again to obtain average, minimum and maximum values. The game screen shows a bright balloon that enlarges with each switch activation. The total number of activations for both trials is recorded. A switch that requires greater effort will result in less activation. Note that this game-based measure of response effort is generally not meaningful for those without an existing access pathway because they often have not developed the requisite skills, e.g. independent activation and switch targeting and release, for this activity.

Rate and immediacy of reinforcement

Rate and immediacy of reinforcement are recorded based on an observation of performance during switch efficacy tasks as well as the response from users and/or caregivers to the following questions.

- On average, how many tries does it take for the user to activate the switch when intended? (estimate of #)
- When the switch is activated, does the software or appliance respond immediately? ('yes'/'no'/'inconsistent' plus comments)
- If the activity is an interactive one with a partner, does the partner provide immediate feedback? ('yes'/'no'/'inconsistent' plus comments)

Quality of reinforcement

Questions related to quality of reinforcement are answered through direct observation of switch efficacy tasks and interviews with the caregiver and/or user.

- Is the switch activation feedback clear and discernible by the participant? ('yes'/'no'/'not sure' plus comments)
- How clearly can the desires of the user be interpreted by the caregiver? (comments)
- Can the access pathway be used in a variety of different contexts, and interfaced with a variety of programs? If not, how is it limited? ('yes'/'no'/'not sure' plus comments)

Appropriateness

Since an appropriate contextual fit is essential for successful technology adoption, it is important to determine whether or not a response efficient switch is also appropriate for the user. ISO 9241-9 defines an appropriate device as one that is effective, efficient and satisfactory for the tasks being performed and the intended work environment [16]. Thus, in addition to response efficiency factors described above, efficacy and satisfaction are measured for each access pathway.

Switch efficacy is measured using a game that is of interest to the user. The sensitivity and specificity of the switch are calculated based on manually recorded performance data (true and false positives, true and false negatives) during the game. Criteria for the game are as follows: requires low cognitive effort, has clear correct and incorrect responses, gives clear feedback and has an adjustable pace. For example, an appropriate game might be one where a computer game character throws a ball. When the ball passes through a box on the screen, the user must hit their switch so that their character, a batter, will hit the ball and achieve a home run. If the switch is hit at the wrong time, the batter misses the ball. There would be audio and visual feedback for both correct and incorrect timing, and the speed at which the ball is thrown would be adjustable.

Satisfaction is measured using the Quebec User Evaluation of Satisfaction with Assistive Technology 2.0 (QUEST 2.0) [17]. The QUEST is a validated self-administered or interview-based questionnaire that requires respondents to rate their satisfaction with their AT on each of the 12 variables using a five-point response scale. The measured variables relate to the environment, the user and the AT [2] and include items such as Ease of Use, Dimensions and Service Delivery. Respondents subsequently identify the three most important variables from their perspective for qualitative analysis [2].

Outcomes measures

Outcome measures should be selected to capture the areas in which changes are anticipated as well as in priority areas for the user/family [7]. In ATDP, we selected three outcomes to measure. Access technology usage is captured using automated data loggers that record each time the switch is activated. Individual goals are captured using a method known as Goal Attainment Scaling (GAS) [18]. This tool helps children and families set realistic goals and focus their attention on a well-operationalized targeted behaviour [18, 19]. Use of GAS, its psychometric qualities and clinical utility in paediatrics are well documented [18, 20–22]. GAS is more sensitive to change than norm-referenced or fixed item measures [22]. GAS results allow individuals with unique goals to be compared in terms of the level of attainment of their goals [20]. This is a critical feature when working with individuals with multiple disabilities as the intervention, and thus the goals, for each individual will be based on their very unique needs and levels of ability. We used a modified version of the GAS scale, with seven levels ranging from -3 to $+3$, to address possible floor and ceiling effects and to further improve its sensitivity [18, 20, 22].

The third outcome is participation which was chosen to reflect the broader impact an access technology is hoped to have. The Assessment of Life Habits (LIFE-H Short Form) is employed to evaluate this outcome [23]. It provides information about the accomplishment of common activities and social roles for individuals with disabilities, within their socio-cultural environment and according to their personal characteristics [23]. Respondents are asked to identify the degree of difficulty with which each habit is typically accomplished, the type of assistance used to accomplish the habit, and the degree of satisfaction with that level of accomplishment [24]. In pediatrics, this questionnaire is typically completed by the primary caregiver [24].

Final interview

To capture information that may be overlooked by the above measures, we also conduct an informal interview during the final visit at the end of the training period. Participants (caregiver and users) are asked to comment upon: their intentions about continued switch use, their subjective perception of the fit between the access technology and individual context, any problems encountered with the switch, if and how these issues were resolved, the perceived value of the assessment/selection/follow-up process, and are any other thoughts or concerns they would like to share. This final interview will be of value both for future steps with the child and family and will also help to inform future improvements to the ATDP methodology.

Case study

We conducted a descriptive, mixed methods case study with three measurement points: at the time of initial assessment and at eight and 16 weeks post-access technology delivery. We selected a participant who had no reliable means of access to an external device (e.g. voice output device or environmental control) to demonstrate the proposed ATDP. The participant missed significant periods of school due to illness during the study. As a consequence, the follow-up period was tracked according to the number of weeks the participant was in school and able to use and train with his switch. Thus, the eight and 16-week period described below did not consist of consecutive weeks as originally intended for the ATDP. Data reported herein were collected by the primary author and the participant's teacher.

Participant description

The participant, referred to as Adam (pseudonym), is a 12-year-old boy who has degenerative hypotonia of unknown cause and developmental delay. He is an only child living at home with his mother and father and attending school as a grade six student in a community classroom. He has a nurse to aid with his care during the day, both at home and school. Adam is tube-fed, has a tracheotomy and has very little movement, either voluntary or involuntary. He experiences frequent, long-lasting seizures commonly triggered by hot weather and fatigue. He is contingently aware, and both his hearing and vision are within normal limits. Adam's mouth is generally ajar unless he is swallowing, and he spends the majority of his time in an upright seated position in his manual wheelchair.

During the first meeting it was determined that Adam had used mechanical button switches in the past, which he operated with both head and finger movements. However, due to the degenerative nature of his condition, he was no longer able to make the movements required to activate those switches. At his initial assessment, his only reliable movements were eye-gaze and facial expressions, particularly smiling. He used both for low-tech, partner-assisted communication.

Initial assessment

Adam's initial assessment took place near the end of the preceding school year and was attended by his mother, his occupational therapist (OT) and one of his regular nurses. His teacher was consulted at a later date for her opinions on how the technology would be used. The Client Information Questionnaire [15] was completed by Adam's mother, with input from the OT.

The desired uses for the new switch as outlined by Adam's caregivers included: (1) independently accessing a computer for tasks such as reading or games; (2) communicating with simple devices like a Step-by-Step [25] with the potential to graduate to augmentative and alternative communication (AAC) software; and finally, (3) participating in class, which, in addition to communication, could involve controlling electronic devices in music and cooking activities. In his classroom, other switch users controlled electronic devices via a PowerLink control unit [25]. Additionally, the switch had to be useable both at home and at school.

Because Adam was already using eye-gaze and his smile for partner-assisted communication, it was assumed that using one of these movements as an access pathway would require the least amount of cognitive and physical effort. While there are several eye-tracking systems on the market, the OT was concerned that Adam would be unable to use these technologies due to the narrow shape of his eyes and his tendency to keep them half-closed. Additionally, these systems are primarily designed for use with AAC software or computer activities (e.g. DynaVox EyeMax), and often require special adaptations for Adam's other desired uses. As a result, we decided to focus on the smile as the most suitable access pathway.

Existing access method

At the beginning of the study, Adam did not have an access technology and was using low-tech partner-assisted methods for communication. Specifically, following a 'yes/no' question, he would be presented with a green 'YES' card on the right and red 'NO' card on the left, and asked to look at the card with his desired response. Occasionally, he would be presented with four options on a board and would be asked to choose the desired response via eye gaze. This was done primarily for learning activities in the classroom. For nearly all other classroom activities he could only participate by proxy. This was his baseline access method against which the new access technology was contrasted.

Technology development

At the time of this study, there were no known smile recognition access technologies on the market. Therefore, a smile switch was developed to meet Adam's needs. Through discussions with the OT, it was decided that a computer vision-based system would be used to capture and transduce the smile into an electrical signal. Solely for the purpose of algorithm development, videos of Adam were recorded using a SONY 1.0 Megapixel HandyCam MPEG-2 while he smiled in response to various yes/no questions. Previous publications report the successful isolation of specific facial features using both visible light video and thermal imaging [26–28]. The algorithm developed for the smile switch makes use of these strategies to conduct a frame-by-frame analysis of the image to identify the area most likely to be the face, and subsequently isolate the region with the greatest probability of being the mouth. Isolation of the face was achieved using colour detection, while mouth detection was based on edge contrast. A change in the morphological features of the mouth area was then used to detect a smile, and an output signal was sent to a DLP-IOR4 4-channel latching relay module to activate an external device connected to the switch. The overall program is outlined in Figure 3(a). Each processing block is detailed below.

A Logitech® Quickcam Pro 9000 was chosen for video capture as it was small, portable, provided high resolution (960×720 pixels) video and was adaptable to different lighting conditions. The camera was mounted on a Slim Armstrong® mounting arm and attached to Adam's wheelchair. The camera was positioned to Adam's left, approximately 25 degrees from the front of his face, to minimize the obstruction of Adam's view. The camera was adjusted so that Adam's face filled a rectangular box superimposed on the output video. This ensured that the view of the camera, and thus the position of the mouth, was consistent with each use, and that only a specific area of the full frame required analysis. Figure 3(b) depicts the setup used throughout this case study.

The image analysis program was written using MATLAB SimuLink. The input video was first converted to the Hue-Saturation-Value (HSV) colour space to facilitate face detection [26, 28]. The video was subsequently cropped down to a 400×400 frame around the face. The ranges of hues representing the colour red (0–0.12 and 0.88–1) were manually defined, as was a saturation threshold corresponding to the amount of red present in the facial skin tone. This threshold is unique to each individual and was empirically set

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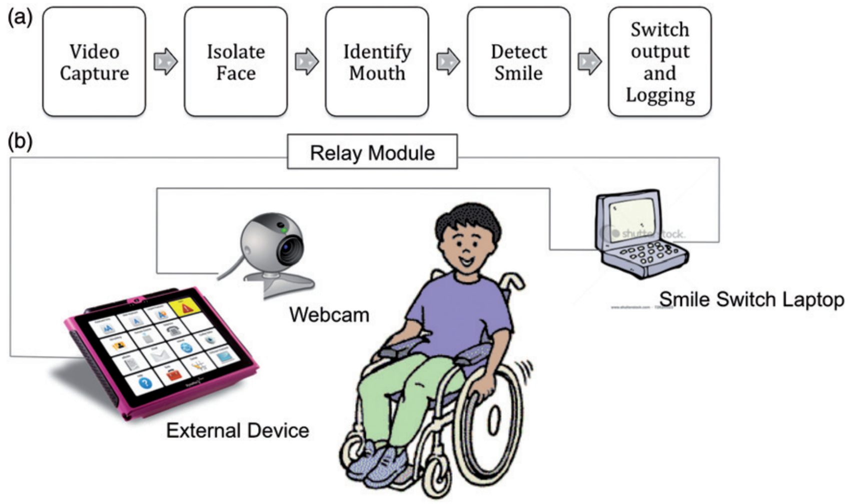

Figure 3. Smile switch program schematic (a) and set up of smile switch for data collection (b).

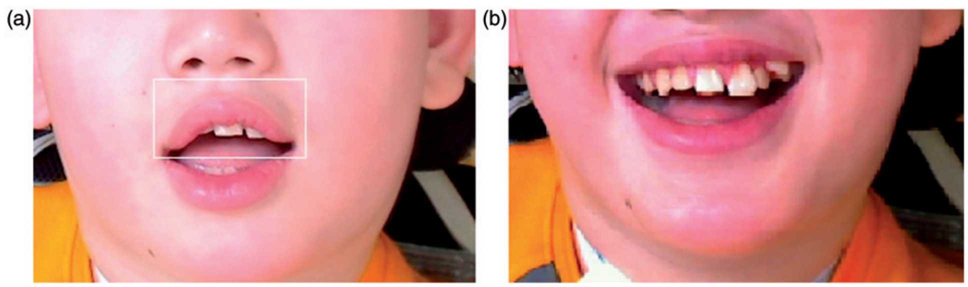

Figure 4. Sample images of relaxed mouth with bounding box (a) and smiling mouth (b).

to 0.6 for Adam. The program identified pixels in the image as skin if their hue values fell within the ranges defined above, and saturation values were less than or equal to the saturation limit (0.6). The face was taken as the largest area that met these constraints, and was isolated using the blob analysis. The region of interest (ROI) was then defined as the bounding box that surrounded the area of the face, which was constrained to the 400×400 frame.

Once the face was detected, the mouth had to be identified. The ROI was filtered using the Sobel Edge Detector. Contrast values for the function were input from the graphical user interface (GUI), where the caregiver selected among three sets of lighting conditions that corresponded to different contrast values. The corresponding contrast values varied with the user's skin tone, and for Adam, these values were set at 20 000, 22 000 and 24 000. The horizontal gradient of the edge detection was used to identify the strongest horizontal edge in the ROI and a grayscale image was output with the identified edges highlighted. A contrast function enhanced the image, creating a black and white frame with only the major edges highlighted. Finally, morphological operations smoothed the image and the largest protruding surface was detected using the blob analysis [27]. Areas of the ROI unlikely to contain the mouth (the upper half of the face and corners of the frame) were effectively masked out.

The last portion of the algorithm was designed to detect whether or not Adam was smiling. The area identified as the mouth was defined by a bounding box around Adam's mouth in the relaxed position. The bounding box persisted as long as the area identified as the mouth met criteria for centroid position, and area and width-to-height ratio. When the shape of the mouth changed from its rest morphology, the above criteria were violated and the bounding box was removed. The user was assumed to be smiling and the program generated a high signal (switch activation block). Note that the switch activated only when the program identified a smile in a number (specified by the user in the GUI) of consecutive frames. Examples of relaxed and smiling mouth morphologies are shown in Figure 4. Additionally, a refractory period was implemented such that upon switch activation, the program must identify the mouth as being in the relaxed position for at least eight frames before the switch can be re-activated. The refractory period minimized the possibility of false positives. Lastly, whenever the switch was activated, a signal was sent to a logging function, which recorded the date and time of the activation, facilitating usage tracking over the period of the study.

Measuring switch efficacy

Data for the sensitivity and specificity measures were obtained over a 2-week period during three evaluation sessions at the end of each of the eight and 16-week stages. The data for all three sessions were pooled and calculations were based on the total counts. During each session, Adam played either 'Splat the Clown' or 'Coconut Shy', both available on helpkidzlearn.com [29]. Both games met our criteria for interest to the user, low cognitive effort, clearly distinguishable correct and incorrect responses, clear feed-back and adjustable pace. In both games, an object would appear on the screen for a set period of time (for Adam, we set that time to 10 s for the coconuts and 'slow' for the clowns) during which he was required to activate his switch to throw the object at either a clown or a coconut. Five hits at the correct time are needed to win the game. In each session, Adam played the game three times during which false positives/negatives and true positives/negatives were recorded. From these observations, sensitivity and specificity were calculated as follows:

$$\text{Sensitivity} = (\text{True Positives})/(\text{True Positives} + \text{False Negatives})$$

$$\text{Specificity} = (\text{True Negatives})/(\text{True Negatives} + \text{False Positives})$$

Results

During the study period, Adam's access technology was primarily used in the school environment, with only occasional use at home. As such, all evaluations for the new access pathway were completed at the school. Switch efficacy data were collected by Adam's teacher based on a standard form and instructions provided by the researcher. All other data were collected by the researcher.

Response efficiency

Adam's teacher answered on his behalf since the 12-point Borg Scale exceeded the maximum four options from which he could independently choose. His teacher felt that his previous means of access (eye gaze) required slightly more cognitive effort than the new switch (going from 'Somewhat Strong' down to 'Moderate'). Initially, the amount of physical effort required for Adam to use the new switch was estimated to be the same as for his previous means of access. However, at the 16-week follow-up the amount of physical effort required had increased from 'Moderate' to 'Somewhat Strong'. This deterioration may be a result of his most recent illness, which occurred just prior to the 16-week follow-up, and changes in his seizure medication that left him with less energy during the day. As seen in the figure, the teacher's perception of the communication partner's effort remained constant at 'Moderate' between the previous and the new access methods.

At the initial evaluation, questions regarding quality, rate and immediacy of reinforcement were focused on Adam's current low-tech communication. With respect to quality, although Adam's mother found it relatively easy to understand his efforts to communicate, his teacher noted that it was sometimes difficult to see his eyes and thus determine the sign (yes or no) at which he was looking. Some of his glances were also very brief and thus deciphering his communicative intent was challenging. If Adam could not be understood, this would be communicated to him and he would be asked to answer again, but in other circumstances, caregivers resorted to their best guess of his answer. His teacher estimated that it would take between 30 and 50 s for her to ask a yes/no question and receive and understand his answer. For multiple-choice questions, the time frame was longer. Because caregivers were not always certain about their interpretation of Adam's answers, it was deemed unlikely that he was receiving the desired response with every communication effort. Thus, the rate of reinforcement was likely low to moderate at best.

At the eight-week period, the new smile switch was evaluated. Adam's teacher reported that they were able to use it in a variety of different settings and with different interfaces. The audio feedback from the switch was very clear and she felt that Adam understood when it was activated. It was also apparent when Adam was trying to use the switch and what he was trying to do with it. At the 16-week period, this pattern continued with the switch being used with a greater number of interfaces including a computer for books and games, a Power Link connected to a fan, a foot bath, a bubble machine or a mixer and a Step-by-Step communication device. Again, feedback for the user was clear, as were his intentions while using the switch. This versatility and clarity marked an improvement in response quality over his previous access pathway.

Adam required approximately 7 s (as estimated by his teacher) to activate the switch at the eight-week period and 5 to 10 s at the 16-week period. This included a 1–4 s delay time between smile initiation and switch recognition of the smile. Once the switch had been activated, an immediate response was received from the software or other interface hardware with which Adam was working. It was reported that the switch was not always consistent from one day to the next; on some days, Adam had to try two or three times before the switch activated correctly, generating the desired response. These observations suggest an improvement in response immediacy over Adam's previous access pathway, but a probable decrease in the rate of response. Overall, the new access technology was at least as response efficient as his previous means of access, and offered better response quality for the targeted tasks.

Appropriateness

Results for measures of efficacy and satisfaction are presented in Figure 5. At the eight-week period, switch sensitivity and specificity were 0.71 and 0.76, respectively, while at the 16-week period, these values changed to 0.78 and 0.64.

The QUEST 2.0 survey was completed by Adam's teacher at the eight- and 16-week follow-ups. At eight-weeks, her overall satisfaction was 3.4 (out of 5) and this increased to 4.5 at 16-weeks. The lowest scoring item both times was 'Effectiveness', with a score of 2 out of 5. The three categories identified as most important were all device-related dimensions, namely, 'Easy to Use', 'Adjustments' and 'Effectiveness'.

Outcomes

Usage

According to the data logger, Adam used his switch on a total of 22 days during the first eight-week period, usually once a day for 1 h at a time. This use averaged between 2 and 3 days

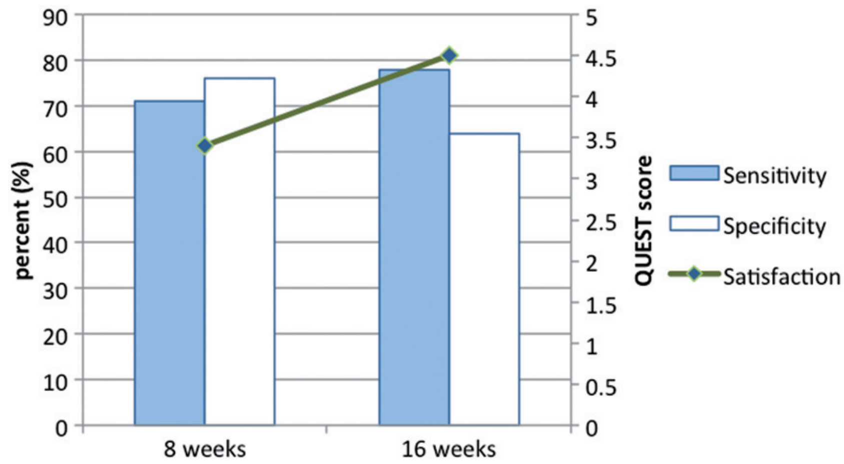

Figure 5. Sensitivity, specificity and satisfaction at eight and 16 weeks.

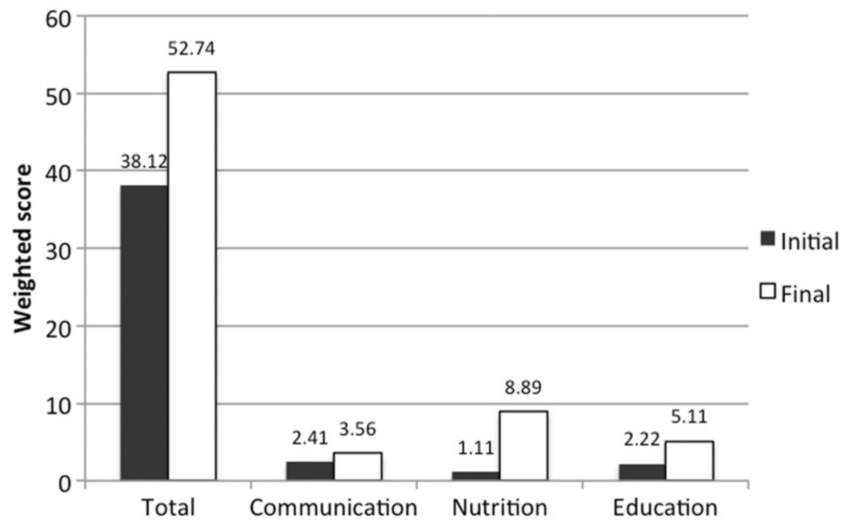

Figure 6. Scores for the LIFE-H for children before and after receiving the new access technology.

per week. During the second eight-week period, Adam used his switch on 28 days, again typically once per day and for 0.5 to 1 h. This amounted to an average usage between three and four times per week. At the end of the study, Adam was still using his switch at the same weekly frequency.

Goal attainment

When Adam's new access technology was delivered, two goals were set by his OT and teacher using GAS in the context of the 16-week study time frame. The first goal was to read and listen to books independently on the computer, and the second was to use a Step-by-Step communication device. Adam would use his switch to access both activities. Goal attainment was scored by his teacher who worked with Adam on both activities. At the eight-week follow-up mark, Adam was still at his starting level (a score of -2) for his reading/listening goal, but had progressed to the 'Somewhat less than Expected' level (a score of -1) with the Step-by-Step goal. However, by the 16-week follow-up, he had reached the 'Expected' Level (score of 0) in reading, and with the Step-by-Step he scored 'Somewhat Better than Expected' (score of $+1$). An improvement of 2 points or greater over the starting value is considered clinically important with GAS [18, 20].

Participation

The LIFE-H was administered with Adam's teacher before he received the new access technology and again at the end of the 16-week period. Results are as shown in Figure 6. The total weighted score at baseline was 38.1 out of 120 points. After delivery of the new access technology and 16-weeks of training, the total weighted score had increased to 52.7. There were increases and decreases in scores across many categories; however, the three showing the most marked increases were directly attributable to activities for which the new access technology was used. These were Education, Communication and Nutrition, specifically the ability to help with meal preparation (Figure 6).

Final interview

The final interview was conducted with Adam's teacher at the 16 week point. She described several difficulties with the switch, including the delay and number of false positives and negatives under certain conditions, particularly if Adam's face was flushed. However, she remarked that they plan to continue to use the switch since it played well to his strengths by focusing on facial expression, could be used for all the required applications, and was portable, allowing mobility among different classrooms and facilitating switch practice at home. Although our follow-up procedure was time-intensive in terms of teacher commitment, Adam's teacher found the process beneficial.

Discussion

Adam's new access pathway was more efficient than his previous means of access in the context of the tasks identified herein. A possible decrease in the rate of response was offset by improved quality and immediacy. This suggests that our assessment and development produced the intended results: an access technology that is more efficient than the user's previous means of access. Additionally, when combined with satisfaction and efficacy results, the assessment appears to result in a technology that is appropriate to the user, as defined by ISO 9241-9. The sensitivity and specificity scores are not ideal, at 0.78 and 0.64 respectively, and unsurprisingly the 'Effectiveness' item had the lowest value in the QUEST 2.0 satisfaction rating. Compromised effectiveness was also reflected in the teacher scoring of the rate of response; multiple attempts were often required before the switch would activate. However, the overall satisfaction rating remained very high (4.5/5.0) and the teacher confirmed in final interview that she felt the switch was a good match for Adam. The high satisfaction result in light of modest sensitivity and specificity suggests that switch accuracy is perhaps over-emphasized as the fundamental outcome of an access technology [26, 30]. Although Adam was unable to give his comments directly, his teacher noted that even when the switch was not activating appropriately, Adam remained motivated and persevered, in her opinion, because he was finally able to control something on his own. Overall, Adam appeared to become more frustrated by false negatives (measured by sensitivity) than false positives. As the sensitivity score became reasonably high by the final measurement stage, and this may explain his continued motivation.

Impact on outcomes is what makes any technology meaningful. In Adam's case, he was using his new technology on a regular basis to participate in activities and control equipment that was previously inaccessible. He accomplished both of the goals set out for him using GAS, and even achieved greater than the expected level for his communication goal. Additionally, there was an overall improvement in his LIFE-H score. It is a very broad measure and thus there are many factors that can influence this score, including health, family situations and funding. Outside of receiving the new access technology, all of these factors were left uncontrolled. As one might expect, there were both positive and negative changes across the categories of the LIFE-H after the 16-week period, reflecting the many changes in Adam's life. However, the overall score did increase after the new access technology was implemented. Furthermore, the three categories that showed the most marked increases in weighted score can be directly connected with activities that Adam is now able to accomplish using his switch. This suggests that access to an appropriate switch alone can have a positive impact on the life of the user, and corroborates previous evidence of the positive impact of access technologies (e.g. Blain et al. [31]). By association, an assessment procedure that results in the delivery of an appropriate access technology can directly lead to this positive impact.

The overall positive impact of the access technology in this case can, in part, be linked with the merits of the proposed ATDP. In the spirit of collaborative practice [32], ATDP engaged a multidisciplinary team guided by a common purpose of enabling access to communication. ATDP flexibly evolved over time, involving teachers, children treatment centre-therapists and family members as required. Collaboration of the inter-professional team, along with caregivers and the user, enriched the interview process; a thorough reassessment of function and abilities was not necessary because those who were most informed were present to provide the necessary information and partake in shared decision-making about the potential access pathway.

It is often tempting to first scan available technology, and subsequently fit the user to a categorical mold. However, the ATDP interview focused on the user's needs and abilities, as opposed to the technology. In this way, the protocol rendered any controlled movement or physiological process an admissible access pathway. By honing in on the user's abilities, ATDP emphasized the choice, creation or modification of a technology to fit the user as a unique individual. In Adam's case, his smile was his best-controlled, personal movement. Finally, the ATDP paired clinicians with a technology-design team, opening up possibilities for access innovations. In the presented case study, no smile-based technologies existed on the market, and the client data collected through the ATDP was used to inform the development of the new switch.

Conclusion

This paper presented a novel, response efficiency-motivated protocol (the ATDP) for the provision of access technologies and demonstrated its potential via a pediatric case study. The protocol featured a multi-stake holder initial assessment, access technology development/selection and a two-stage evaluation procedure. Although the case results were positive, the procedure needs to be further validated with more children having severe and multiple disabilities.

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Declaration of interest

The authors report no declarations of interest. The authors alone are responsible for the content and writing of this paper.

References

1. Lindsay S. Perceptions of health care workers prescribing augmentative: Alternative communication devices to children. Disability & Rehabilitation: Assistive Technology 2010;5(3):209–222.
2. Stickel MS, Ryan S, Rigby PJ, Jutai JW. Toward a comprehensive evaluation of the impact of electronic aids to daily living: Evaluation of consumer satisfaction. Disability & Rehabilitation 2002;24(1–3):115–125.
3. Hoppestad BS. Inadequacies in computer access using assistive technology devices in profoundly disabled individuals: An

overview of the current literature. Disability and Rehabilitation Assistive Technology. 2007;2(4):189–199.
4. Hoppestad BS. Essential elements for assessment of persons with severe neurological impairments for computer access utilizing assistive technology devices: A Delphi study. Disability and Rehabilitation Assistive Technology 2006;1(1–2):3–16.
5. Elsaesser L, Bauer SM. Provision of assistive technology services method (ATSM) according to evidence-based information and knowledge management. Disability & Rehabilitation: Assistive Technology 2011;6(5):386–401.
6. Bernd T, Van Der Pijl D, De Witte LP. Existing models and instruments for the selection of assistive technology in rehabilitation practice. Scandinavian Journal of Occupational Therapy 2009; 16(3):146–158.
7. Scherer MJ. Outcomes of assistive technology use on quality of life. Disability & Rehabilitation 1996;18(9):439–448.
8. Scherer MJ. The change in emphasis from people to person: Introduction to the special issue on assistive technology. Disability & Rehabilitation 2002;24(1–3):1–4.
9. Ripat J, Woodgate R. The intersection of culture, disability and assistive technology. Disability & Rehabilitation: Assistive Technology 2011;6(2):87–96.
10. Tai K, Blain S, Chau T. A review of emerging access technologies for individuals with severe motor impairments. Assistive Technology 2008;20(4):204–219.
11. Johnston SS, Evans J. Considering response efficiency as a strategy to prevent assistive technology abandonment. Journal of Special Education Technology 2005;20(3):45–50.
12. Mace FC, Neef NA, Shade D, Mauro BC. Effects of problem difficulty and reinforcer quality on time allocated to concurrent arithmetic problems. Journal of Applied Behavior Analysis 1996; 29(1):11–24.
13. Neef NA, Mace FC, Shade D. Impulsivity in students with serious emotional disturbance: The interactive effects of reinforcer rate, delay, and quality. Journal of Applied Behavior Analysis 1993; 26(1):37–52.
14. Johnston SS. Considering response efficiency in the selection and use of AAC systems. Journal of Speech and Language Pathology and Applied Behavior Analysis 2006;1(3):193–206.
15. Memarian N. A novel access technology based on infrared thermography for people with severe motor impairments. Toronto: University of Toronto; 2010.
16. ISO. ISO 9241-9 ergonomic requirements for office work with visual display terminals: Part 9 requirements for non-keyboard input devices; 2000.
17. Demers L, Monette M, Lapierre Y, Arnold DL, Wolfson C. Reliability, validity, and applicability of the Quebec user evaluation of satisfaction with assistive technology (QUEST 2.0) for adults with multiple sclerosis. Disability & Rehabilitation 2002; 24(1–3):21–30.
18. Tam C, Teachman G, Wright V. Paediatric application of individualised client-centred outcome measures: A literature review. British Journal of Occupational Therapy 2008; 71(7):286–289.
19. Di Rezze B, Wright V, Curran CJ, Campbell KA, Macarthur C. Individualized outcome measures for evaluating life skill groups for children with disabilities. Canadian Journal of Occupational Therapy [Revue Canadienne D'Ergothérapie] 2008;75(5):282–287.
20. Cusick A, McIntyre S, Novak I, Lannin N, Lowe K. A comparison of goal attainment scaling and the Canadian occupational performance measure for paediatric rehabilitation research. Pediatric Rehabilitation 2006;9(2):149–157.
21. McDougall J, King G. Goal attainment scaling: Description, utility and applications in pediatric therapy services. 2nd ed. London, Canada: Thames Valley Research Centre and CPRI; 2007.
22. McDougall J, Wright V. The ICF-CY and goal attainment scaling: Benefits of their combined use for pediatric practice. Disability and Rehabilitation 2009;31(16):1362–1367.
23. INDCP: International Network on the Disability Creation Process – In Québec: Knowledge development and diffusion [Internet] [cited 2010 June 7]. Available from: http://www.ripph.qc.ca/?rub2=4&rub=15&lang=en
24. Fougeyrollas P, Noreau L, Lepage C. Assessment of life habits: Childrens short form. Lac-Saint-Charles, Canada: International Network on the Disability Creation Process; 2003.
25. Assistive Technology Products and Services for Persons with Disabilities [Internet] [cited 2011 July 12]. Available from: http://www.ablenetinc.com/
26. Leung B, Chau T. A multiple camera tongue switch for a child with severe spastic quadriplegic cerebral palsy. Disability & Rehabilitation: Assistive Technology 2010;5(1):58–66.
27. Memarian N, Venetsanopoulos A, Chau T. Infrared thermography as an access pathway for individuals with severe motor impairments. Journal of NeuroEngineering and Rehabilitation 2009;6:11–18.
28. Nguyen D, Halupka D, Aarabi P, Sheikholeslami A. Real-time face detection and lip feature extraction using field-programmable gate arrays. IEEE Transactions on Systems, Man and Cybernetics 2006; 36(4):902–12.
29. HelpKidzLearn [Internet] [cited 2011 July 16]. Available from: http://www.helpkidzlearn.com/games.html
30. Alves N, Falk TH, Chau T. A novel integrated mechanomyogram-vocalization access solution. Med Eng Phys 2010;32(8):940–944.
31. Blain S, McKeever P, Chau T. Bedside computer access for an individual with severe and multiple disabilities: A case study. Disability and Rehabilitation Assistive Technology 2010; 5(5):359–369.
32. Canadian Interprofessional Health Collaborative. A national interprofessional competency framework. Vancouver, BC: University of British Columbia; 2010.