Exploring Ways to Engage Children with Cerebral Palsy

Miyako Jones

School of Electrical and Computer Engineering

Faculty Advisor: Dr. Ayanna Howard

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Abstract—Cerebral palsy is a term used for a group of nonprogressive, incurable brain disorders that affect motor control. There are four different types—spastic, dyskinetic/athetoid, ataxic, and mixed—with spastic being the most common. The main symptom of spastic cerebral palsy is stiff muscles. The subtypes are categorized by the number of limbs affected and the quality of movement. The affected limb(s) of individuals with dyskinetic cerebral palsy make uncontrollable writhing movements, individuals with ataxic cerebral palsy have poor balance and coordination, and individuals with mixed cerebral palsy have symptoms of two or more types.

Many children with cerebral palsy have difficulty using their hands for tasks; however, toys have a significant impact on a child's cognitive, social, and physical development. This paper explores the possibility of using the Boardmaker® Plus! special needs educational software to develop an interface to provide alternative access to toys.

I. INTRODUCTION

A. Background

The term *cerebral palsy* encompasses several nonprogressive conditions that affect motor control whose onset occurs prior to birth or during early childhood. The National Dissemination Center for Children with Disabilities (NICHCY) estimates that about 500,000 people in the United States are living with some form of cerebral palsy, and 8,000 infants and nearly 1,500 preschool-aged children are diagnosed with cerebral palsy each year. Over the last 30 years, the percentage of children born who will develop cerebral palsy has remained about the same despite advancements in medical care due to the higher survival rates of premature infants. Symptoms of cerebral palsy include lack of muscle coordination; stiff or tight muscles; walking with one leg or foot dragging, or on the toes; tremor or random involuntary movement; variations in muscle tone (too stiff or too loose); difficulties swallowing or speaking; and difficulty with precise movement. Although the symptoms primarily affect motor control, cerebral palsy is a condition of the brain. Some early warning signs of cerebral palsy are developmental delay in infants and toddlers such as being slow to learn how to roll over, to smile, and to crawl; abnormal muscle tone; and abnormal posture.

A successful diagnosis of cerebral palsy is made when the doctor has determined that all of the usual symptoms are present and the condition is not progressive. Neuroimaging is often used to rule out other conditions that cause the same symptoms as cerebral palsy. A cranial ultrasound is used on premature infants because it is the least intrusive; a computed tomography (CT) scan shows brain structure; and a magnetic resonance imaging (MRI) scan uses a computer, a magnetic field, and radio waves to show brain structure and tissue. Of the three types, an MRI scan is the most successful at showing damage to the brain.

Cerebral palsy is caused by damage to the brain. For the vast majority, the brain damage has occurred prior to birth. It can also occur after, however, due to brain damage, a brain injury, or disease. For over a century, this was the accepted cause despite argument to the contrary provided by Sigmund Freud in 1897 [1]. It was not until the 1980s that extensive research was conducted on cerebral palsy, and it was discovered that the damage usually occurred prior to birth. There are four types of brain damage known to cause congenital, or pre-birth, cerebral palsy: damage to the white matter of the brain (which transmits signals to the rest of the body); abnormal brain development due to conditions such as genetic mutations, maternal disease, and trauma; bleeding in the brain, often caused by fetal stroke; or brain damage caused by lack of oxygen during labor and delivery [1]. Premature infants are twice as likely to develop cerebral palsy. A 1993-2001 NIH study documented that two-thirds of the premature infants in the study developed an infection and 16% of those infected developed cerebral palsy [2]. Half of all children with cerebral palsy were born prematurely [2].

Congenital cerebral palsy related to genetic mutation cannot be prevented, but one way to prevent other causes of congenital cerebral palsy is for a woman to be vaccinated against *rubella*, or German measles, before becoming pregnant. Acquired cerebral palsy can be prevented by practicing child safety techniques such as using a car seat and being careful during bath time. The use of fetal monitoring machines to track an unborn child's heartbeat during labor or the use of an emergency cesarean section when significant fetal distress has been detected have not been proven to reduce the number of infants born with cerebral palsy [1].

There are several different types of cerebral palsy, all of which are classified by the type of movement disorder and any additional symptoms [1]. *Spastic* (stiff muscles), *athetoid* (writhing movement), or *ataxic* (poor balance and coordination) are all types of movement disorder. There is also a common mixed type which includes the symptoms of two or more movement types. The spastic type, which is the most common, is further divided into subtypes based upon the severity of the condition and the number of limbs it affects. *Spastic hemiparesis/hemiplegia* usually affects the hand and arm on one side of the body but can also include the leg, *spastic diparesis/diplegia* affects mostly the legs, and *spastic quadriparesis/quadriplegia* affects all four limbs and is often accompanied by mental retardation because of the severity or spread of brain damage. The intelligence of children with cerebral palsy is usually not affected but language skills often are due to lack of muscle control. The intelligence of children with s*pastic diparesis/diplegia* is usually unaffected as is their language skills.

There are many conditions associated with cerebral palsy due to the fact that it is caused by brain damage and the brain controls the body. Many individuals with cerebral palsy have no additional condition; however, those who do may have to cope with the additional condition being more difficult to manage than their cerebral palsy [1]. Cerebral palsy can cause seizure disorders; hearing, vision, and speech impairment; delayed growth and development; incontinence, spinal deformities; mental retardation; drooling; and abnormal sensations and perceptions.

While cerebral palsy cannot be cured, it can be treated. There is no standard treatment plan as it depends on the type of cerebral palsy diagnosed, the severity of the condition, any associated conditions, and the child. Types of treatment include drugs, physical therapy, speech therapy, occupational therapy, surgery, counseling, and assistive devices such as hearing aids, leg braces, and wheelchairs. Each individual has a team of professionals who work with him or her and his or her parents/caregivers to develop a treatment plan. Members of the team often include a physician, an orthopedist, a physical therapist, an occupational therapist, a speech and language pathologist, a social worker, a psychologist, and an educator.

B. Motivation

In the United States, the Individuals with Disabilities Education Act (IDEA) states that children with a physical or mental disability outlined in IDEA are entitled to "a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living." [3] An early intervention system known as an Individualized Family Services Plan (IFSP) is available for infants and toddlers while an Individualized Education Program (IEP) is developed for school-age children. Both are developed for each child's individual needs. Children with physical disabilities such as cerebral palsy often require special equipment in the classroom such as communication boards, voice synthesizers, and switch devices. This equipment is known as *assistive technology* (AT). Other types of assistive technology include electric wheelchairs and leg braces. States are responsible for meeting the special education needs of students [4]. The Assistive Technology Act of 1998 was created by Congress to "support programs of grants to States to address the assistive technology needs of individuals with disabilities" [5]. Despite these measures, access to technology remains unequal and persons with severe or multiple physical and mental disabilities are largely overlooked. According to Hoppestad, disabled individuals are "typically underserved" due to "their own lack of knowledge, limited availability of trained personnel and a dearth of resources." [6]

Internationally, laws vary widely. In developing nations in particular, disabled children are very unlikely to attend school, get a job, or have a social life. The disabled children of the world make up the "largest and most disadvantaged minority" [7]. In 1989, the United Nations adopted the Convention of the Rights of the Child (CRC) which includes a specific article on the rights of disabled children (article 23). Article 24 of the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD) specifically mentions the education of disabled children. Article 32 of the CRPD stresses that international cooperation is necessary to realize the objectives of the convention.

II. THEORY

Assistive technology is available for people who have problems communicating with others, both traditional and computer-based. This subtype of AT is called Augmentative and Alternative Communication (AAC). The user's physical ability has a major impact on the selection of the device used as does the level of the user's intelligence and their age. There are two types of AAC: unaided and aided. Unaided forms consist of "natural communication" such as pointing or eye gazing while aided forms require an external device such as a communication board or a computer [10].

Physical devices that provide access to aided AAC for individuals with cerebral palsy usually fall into the category of joystick or switch, with the former allowing multidirectional movement as well as option selection and the latter only allowing selection. These devices range from simple to complex, from $45 to over $2,000 (according to the AbleNet Inc. website). They can be purchased in a variety of sizes, colors, and textures. Most are meant to be used with the hand, but there are also head switches, foot switches, mouth switches, and even switches that can detect muscle movement.

Aided AAC for individuals with cerebral palsy is usually achieved by a method called row/column scanning, which has been in use since the early 1970s, but it requires more cognitive ability and more muscle control for successful use than horizontal only scanning and vertical only scanning [11]. Early implementations of this method focused only on spelling words and communicating mathematical equations. Possible selections are highlighted by the software one at a time, first by row and then by column (if necessary). The user then pushes his or her switch to make a selection. This type of scanning is called auto-scan, which is the most common type amongst assistive software. There is also an inverse scan type that uses a switch to control the advancement of the scan instead of the option selection and a step-scan type that uses two switches: one to control the scan and one to make a selection. However, not all types of scanning work well with all types of cerebral palsy. Proper selection of scanning type depends on the user's type of cerebral palsy, his or her level of cognitive ability, and the cursor speed [11]. Another important consideration is the user's tracking and visual skills [10]. The level of individual performance with each type should be compared before making a final selection.

In a 1966 study conducted by the Crotched Mountain Foundation of Greenfield, New Hampshire, a number of different joysticks and switches were tested on 13 individuals with various types of cerebral palsy. The basic purpose of the study was to develop electronic devices to extend the capability of a handicapped child when all other avenues leading to physical independence had been exhausted [13]. It was thought that the research would eventually allow such a child 1) some control over his or her environment, 2) the ability to communicate with the outside world, 3) the ability to operate machinery with the possibility of becoming employable, and 4) greater success at a task (which would then lead to the motivation to improve his or her capability). There were seven different types of input devices used in the study: three types of joysticks and four types of switches. Each device had four selection options: up, down, left, and right. The selections were controlled by either a single switch capable of being moved in multiple directions or by four separate switches.

The Crotched Mountain study found that certain physical requirements must be met in order for the operation of a particular input device to be successful. To use a joystick, the individual's arm must be able to remain in a particular position for an extended period of time. He or she would then be able to grasp the handle of the joystick or manipulate it with his or her thumb. The head switch requires the user to be capable of moving his or her head laterally as well as up and down. The tongue joystick proved to be unusable for all individuals as it was too sensitive to allow a high degree of accuracy and too small to be used with the hand. The potential of such a device is still being researched today as an alternative to the sip-and-puff switch. At the time of the study, the sip-and-puff switch could not be used reliably with an output device, but it was used to train the subjects on "lip closure and sucking control" [13]. Only two of the thirteen individuals could operate the hemispherical switch due to the tilting motion required. The magnetic switch was the most successful as it could be reconfigured. A magnet could be attached to a rod that could be gripped, a hand, a foot, or a mouth stick. When the magnet was manipulated by the hand, sufficient hand and forearm control were required to prevent accidental switch activation by passing too close. The slammer switch, or the "horn button", was not as successful as they would have liked as it behaved unreliably.

Prior to the widespread use of personal computers, assistive input devices could only operate simple output devices meant to perform only one or two tasks. Toys could be controlled with them, but only if they were electronic. The Crotched Mountain study used four output devices: a display board with four light bulbs, an Etch-A-Sketch drawing toy, a strip-projector belonging to one of the subjects, and an electric typewriter. The display board was used to test all of the switches and showed much promise. It was discovered that testing nonverbal, severely handicapped children on the concept of up, down, left, and right was difficult. Instead, they used letters, symbols, and pictures to test their control and, later, colored light bulbs. The Etch-A-Sketch's knobs could be controlled by special motors, enabling the children to create simple line drawings. The owner of the strip-projector was able to control it and the researchers considered it a possible alternative to the page-turners available at the time as reading material could be transferred to film. The electric typewriter was introduced late in the study, and only four of the participants tested its functionality. Thirty-two lighted characters were displayed on a 4x8 matrix. Control was limited to left, right, up, and down. After a selection was made, half the remaining lights in the quadrant would turn off so that, ultimately, only the desired letter would remain lit.

Any additional movements after that point were to print the character, reset the display, etc. They believed that the sequence could eventually be learned so well that the display board would not be needed.

Assistive devices can help children with cerebral palsy actively participate in their life. However, there are few toys designed for children with special needs, and the toys are almost always electric so that switches can be plugged into them. Existing toys can be adapted, but the skill and expense required may be prohibitive. One way to avoid this is by reconfiguring existing software to control devices. What is used for education could possibly be used for recreation. There are a few switch-accessible software titles that will allow the creation of activities by the user: Boardmaker® Plus! by Mayer-Johnson LLC., ChooseIt! Maker by Inclusive Technology Ltd., and Communicate: By Choice by Widgit Software. Only Boardmaker® Plus! allows interaction with external applications.

III. APPROACH

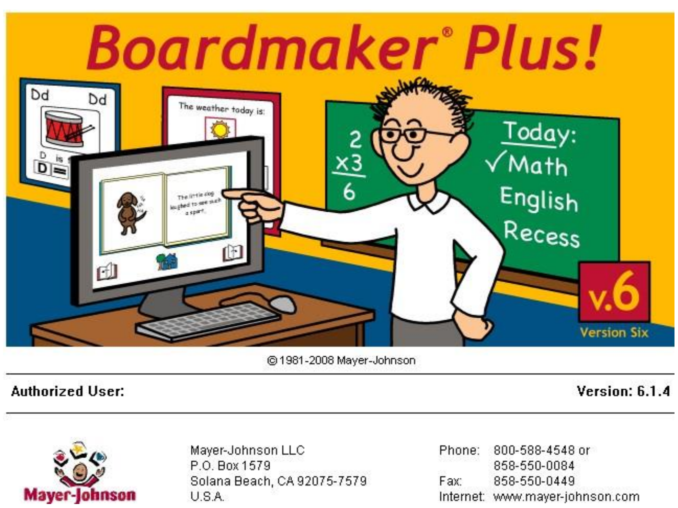

Figure 1: About Boardmaker® Plus! screen.

Boardmaker® is a computer program for educators introduced in 1990 that creates printed educational and AAC materials. Boardmaker® Plus! takes the original idea and adapts it for onscreen use. All versions of the software use Mayer-Johnson's Picture Communication Symbols (PCS), which were designed for students with special needs in 1981. The program's workspace is called a *board*.

Within Boardmaker® Plus!, buttons are created to allow user interaction with a board after it is put in use mode. A user can choose the size, color, and border of a button; and add text in various font faces, colors, sizes, and styles. Images or PCS can also be added. Buttons can also have action lists, which greatly increase the quality of the user experience. A button can change a setting, load another board, activate a video or play a sound, type messages, and launch external applications. For example, a board could be used as an alternative desktop with buttons acting as shortcuts to frequently-used programs. The buttons can also be configured to store variables, launch macros, or activate only if certain conditions have been met. The text features use buttons to act like an onscreen keyboard for AAC users. It can also predict the words a user intends to type to aid the process.

Boardmaker® Plus! offers methods of access for a variety of users. There is touchscreen access; head mouse access; auto-, step-, and inverse scanning access for use with switches (all of which use the row/column method); and joystick access. Standard mouse buttons and the keyboard arrow keys are supported as well. All options can be configured for individual needs.

As there are so many options, Boardmaker can be used to create an interface for just about anything. The built-in control options for assistive devices allow physically disabled users to interact with it independently. A button can launch any program by loading it directly or by using a document to load it indirectly. The interface created for the project demonstrates

Boardmaker's ability to facilitate access to non-AT devices.

The interface has three main boards. The first board contains a graphical representation of a piano with four primary "keys" (blue, green, yellow, and orange) and a button for each double-key note (blue-green, green-yellow, and yellow-orange). These keys are in a scanning group. The scan will loop indefinitely through a group in a set pattern as long as the user makes at least one selection. If no selection has been made, the scan will loop as many times as indicated in the scanning options before exiting the group. Upon selecting one of the keys, Boardmaker will load a specific DOS batch file and pass an argument to it. The argument will then be used to select a particular sequence of commands to send to a robot connected to the computer that will play a physical toy piano. For example, selecting the blue key will open the batch file and pass the argument "blue-key" to it. The "blue-key" commands will then be located and "echoed" to the robot, which will then hit the blue key on the piano. On the bottom of the board are two buttons that belong to a "board navigation" scanning group: one to advance to the first song board and one to quit the program. By default, the program loops indefinitely through a top-level group that contains the piano key group and the board navigation group.

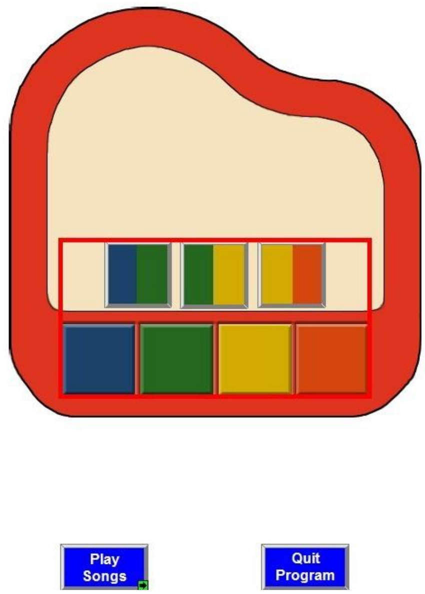

Figure 2: Piano display board with key scanning group highlighted.

```
:BLUE-KEY

echo #4 P2050 >com4
echo #0 P1875 >com4
ping -n 2 127.0.0.1 >nul

echo #2 P1925 >com4
echo #2 P1840 >com4
ping -n 2 127.0.0.1 >nul

EXIT


:BLUEGREEN-KEY

echo #4 P800 >com4
echo #0 P1920 >com4
ping -n 2 127.0.0.1 >nul

echo #2 P1925 >com4
echo #2 P1840 >com4
ping -n 2 127.0.0.1 >nul

EXIT
```

Figure 3: A portion of the batch file used to send commands to the robot. Code developed by Terrence Trapp, a member of the research group.

The third and fourth boards contain songs that can be played using the seven notes of the piano. Three of them are classic children's songs (Mary had a Little Lamb; Twinkle, Twinkle Little Star; and Row, Row, Row Your Boat) while the fourth is an original composition. The name of each song is placed on an invisible button so that the user can select the song by selecting its name. Doing this will also instruct Boardmaker to load the batch file and pass an argument to it. The robot will be instructed to hit the series of keys that make up the tune as illustrated on the two song boards. The songs were composed by Naquasia Jones, who is a member of the research group. Beneath each song title is the sequence of keys that make up the tune and the lyrics (if applicable). The navigation scanning group at the bottom of each song board includes a button to change to the second song board, a button to change to the piano key board, and a quit program button.

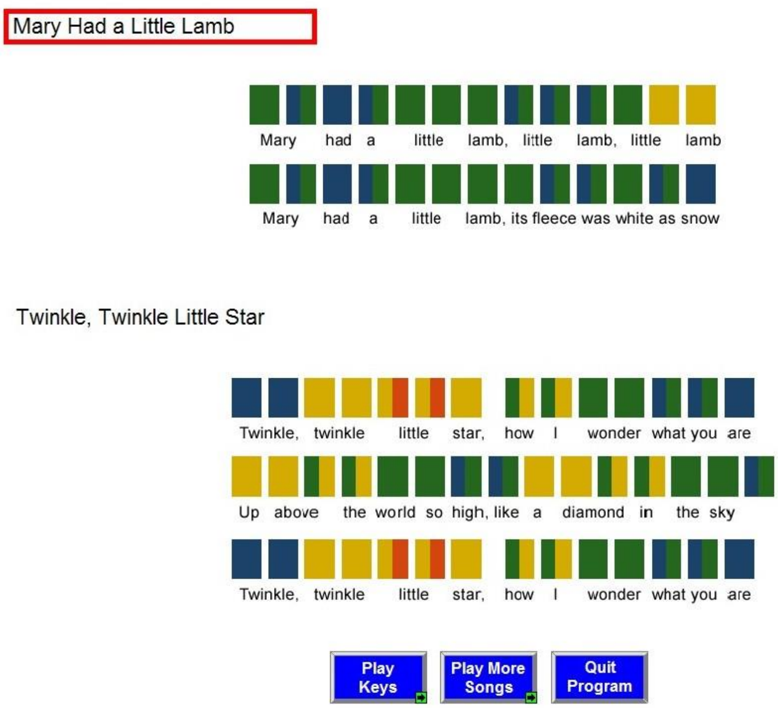

Figure 4: First song board with song button highlighted.

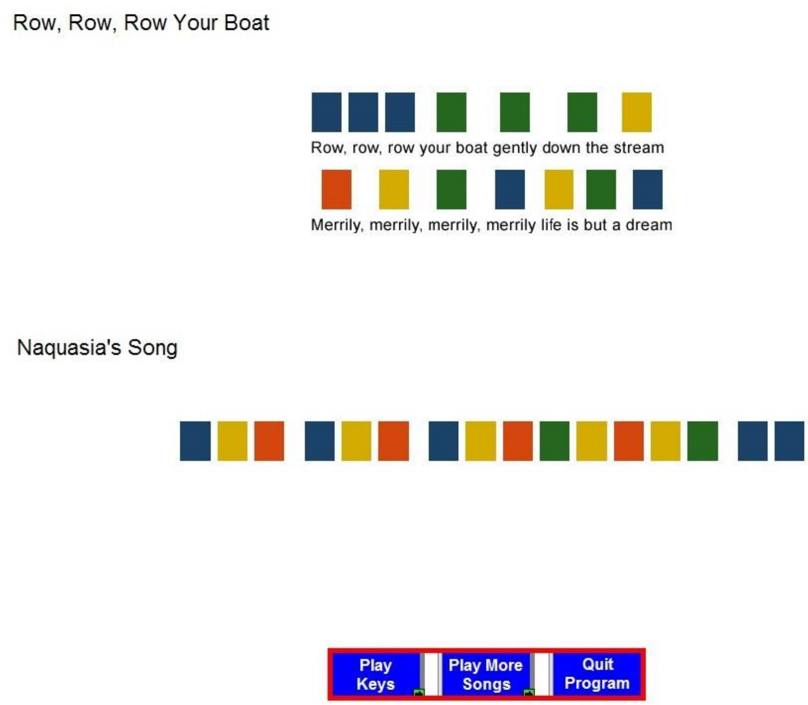

Figure 5: Second song board with navigation scanning group highlighted.

It was important to consider the layout of the board while placing items. Similar buttons should be grouped together. If using multiple boards, buttons should be consistently placed in order to assist the user with locating selections. Standard visual design rules also apply. Colors should have high contrast and low intensity. There should also be adequate "negative space" between each element.

Using a switch for access is often as easy as plugging it into the computer through a switch interface. Switches use a 1/8 inch plug like the one used to plug a pair of headphones into an MP3 player or speakers into a computer. However, a switch will not work if plugged directly into a computer. A switch interface is needed in order to connect the two together by providing a port for the switch and an input for a USB, serial, or PS/2 port on the computer. Once connected, Windows 2000 or newer will automatically configure the device for use. Switch interfaces can connect one switch to the computer or multiple switches simultaneously.

The QuizWorks USB switch interface used for the project allows up to four switches to be connected at once and has templates to enable the emulation of different keyboard keys or mouse buttons. Two different switches were tried—a traditional wired one by QuizWorks and a wireless one by AbleNet that used a wired receiver. The wired one was more accurate and more responsive. This does not prove that wired switches are always better as outside radio interference or a malfunction with the switch itself could have affected its performance. The wired switch was rectangular and only the end opposite the connection cable could be pressed. The base of the switch was also only about a quarter inch in height. The wireless switch was circular and the entire switch could be pressed. The base was about five inches high. Both the switch and receiver required two AA batteries for operation and each had an on/off switch.

IV. FUTURE WORK

Batch file programming was required to make the robot respond to the commands given to it by the Boardmaker interface. It is not possible to command it to do something not defined on one of the boards without editing the batch file. A future version of assistive control software should allow device customization within the program itself so that it will be easier to make behavioral modifications. In the meantime, programming a robot to respond to general commands such as “left” and “right” when using the Boardmaker interface would give a child with cerebral palsy significant control over their play time.

V. CONCLUSIONS

Computer software is usually not adapted for alternative access methods and those that are often restrict the user to one type of activity. Boardmaker® Plus! is a different type of special needs software. It allows the user to launch applications externally, giving a switch user access to programs that were previously unavailable to them. Through Boardmaker, it is also possible for the user to access a nonadaptive device when it is connected to the computer.

Boardmaker's ability to process variables and conditional statements make it a viable platform for assistive software development. In addition, alternative access methods are built in. One significant disadvantage to this method is being required to install Boardmaker and have the CD in the drive in order to use a board. For developers who need a stand-alone program, Boardmaker could be used as a starting point.

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