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THE EFFECT OF CONTINGENT AUDITORY STIMULATION OF SELF-INITIATED MOVEMENT ON THREE QUALITY OF LIFE MEASURES IN YOUNG CHILDREN WITH SEVERE MULTIPLE DISABILITIES

By

Cathy H. McQuillan

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ABSTRACT

THE EFFECT OF CONTINGENT AUDITORY STIMULATION OF SELF-INITATED MOVEMENT ON THREE QUALITY OF LIFE MEASURES IN YOUNG CHILDREN WITH SEVERE MULTIPLE DISABILTIES

By

Cathy H. McQuillan

This study investigated the effect of providing musical stimulation, both contingent to movement and noncontingent to movement, on 3 quality of life factors in 2 children, aged 4 and 6 years, who have severe multiple disabilities (SMD). The contingent musical stimulation was provided by a movement sensor system called Soundbeam. The Soundbeam system consists of a beam emitter, control box and electronic keyboard. Movements that interrupt emitter beam produce sound on the keyboard.

The assessments used to measure the effect of this intervention were: (a) quality of behavior state as measured by the amount of time in states considered optimum for learning; (b) amount of enjoyment of the activity as measured by observation of indices of happiness; and (c) amount of voluntary movement as measured by observation of these movements.

The investigator used a single-subject multiple baseline design of A-BC-B-BC across the 2 participants. Experimental sessions were conducted 3 times a week over a period of 13 weeks in the participants' homes. During the baseline phase (which consisted of 3 sessions for the first participant and 6 sessions for the second participant) each participant had access to a preferred leisure activity while seated in her wheelchair.

During the first intervention phase which consisted of 15 sessions, the Soundbeam emitter was positioned near the participant in such a way that voluntary movements the child was capable of making activated the instrument. During the third phase which consisted of 6 sessions, the investigator removed the emitter and produced the musical feedback with her movements, thus the participant heard the music but did not have control over it. In the fourth phase, which consisted of 15 sessions for the first participant and 12 sessions for the second participant, control of the instrument was returned to the child.

Data for the 3 quality of life factors were collected using observational protocols. The data were graphed for visual analysis, effect sizes of the difference in means of the 4 phases were calculated, and field observations of the investigator were reviewed. Analysis of the data indicated that the introduction of the intervention had different effects on the 2 participants. The first participant exhibited a decrease in observed indices of happiness after the first introduction of Soundbeam and no changes in the other 2 measures across all 4 phases. The second participant exhibited a decrease in preferred state intervals, an increase in indices of happiness, and an increase in voluntary movement after the first introduction of Soundbeam.

It was concluded that this investigator did not find significant evidence that Soundbeam was effective in improving the quality of life factors of these participants. Discussion focused on the usefulness of multiple quality of life assessments in detecting behavioral changes in children with SMD, possible effects on family members when the child is in a contingent situation, and the role of behavior state in the lives of children with severe multiple disabilities.

DEDICATION

This dissertation is dedicated to the memory of four very special children; Karen, Jonathan, Jacob, and Kirstie Ann. You live on in the hearts of all who loved you. It was a privilege to have been your teacher.

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CHAPTER 1

Introduction

Overview of the Problem

The provision of educational services to children with multiple disabilities in the United States has been mandated for over three decades. Many of these students first gained access to public education as a result of a Federal law, Public Law 94-142 passed in the mid 1970's (Siegel-Causey, Guy, & Guess, 1995). Public Law 94-142, titled the Education for all Handicapped Children Act, mandated universal access to education for all children, regardless of disability. Children receive support services and accommodations according to their needs, which are categorized by disability.

Children who qualify for services in the category of multiple disability are a heterogeneous group with a wide range of ability levels and support needs. Children identified as having multiple disability currently comprise less than 2% of the total population of students receiving special education services (United States Department of Education, 1995).

One subset of students with multiple disabilities is that of children who have severe multiple disabilities (hereafter SMD). Children who have SMD have been described as those children whose cognitive abilities are measured at less than twelve month levels, have various degrees of sensory loss, and are typically non-ambulatory and non-verbal (Arthur, Hook, & Butterfield, 1995). The education of children with SMD presents a great challenge to educators and caretakers as few effective interventions have been identified, it is difficult to appropriately assess these students and there is disagreement about appropriate educational goals for this population.

Significance of the Problem

The intense needs of SMD students place great demands on the financial, physical, and emotional resources of caretakers and school systems. Providing educational services to this population of students requires support from a wide range of professionals (Dule, Korner, Williams, & Carter, 1999). Classroom teachers report dissatisfaction with training and lack of time to adequately serve this population of children (Izen & Brown, 1991). Large blocks of classroom time must be devoted to maintaining the health and safety of the children (Campbell, 1987; McCubbin, 1987) in addition to providing educational interventions.

Descriptions provided by researchers help convey the pervasive effects that SMD have on the individual's functioning. Morse (1992) describes a child with SMD:

> Wally, aged 5, has been diagnosed with cortical blindness and a severe seizure disorder. He also is physically impaired and lives most of his day in a wheel chair . . . Wally generally gazes into space . . . he will briefly fixate on an appealing stimulus at a distance of 8"-12" or near eye level. His left hand usually is clenched and positioned on his tray near his chest. His right hand sometimes engages in small random side-to-side swiping motions. Wally alerts to sudden sounds by "startling," during which his entire body extends and his eyes widen. (p. 74)

Children with SMD are totally dependent on others to meet all of their daily living needs. Parents have written poignant accounts of the almost overwhelming demands the child with SMD places on the family (Featherstone, 1980; Kupfer, 1982; Morton, 1978). For example, Featherstone (1980) expressed her reaction to an additional 15-minute care routine suggested by a school nurse:

> This new demand appalled me. I rehearsed angry, self-justifying speeches in my head. Jody, I thought, is blind, cerebral-palsied, and retarded. We do his physical therapy daily and work with him on sounds and communication. We feed him each meal on our laps, bottle him, change him, bathe him, dry him, put him in a body cast to sleep, launder his bed linens daily, and go through a variety of routines designed to minimize his miseries and enhance his joys and development

> . . . where is that fifteen minutes going to come from? What am I supposed to give up? . . .because there is no time in my life that isn't spoken for, and for every fifteen-minute activity that is added, one has to be taken away. (p. 77-78)

Debate continues as to the most suitable and efficacious ways to provide an appropriate education for children with SMD. There is emerging consensus that curricula used for children with mild and moderate disabilities are not appropriate for children with more severe disabilities (Ayres, Meyer, Erevelles, & Park-Lee, 1994; Ferguson, 1985; Sailor, Gee, Goetz, & Graham, 1988; Westlake & Kaiser, 1991). Children with SMD will probably never attain the vocational or self- care skills that are the desired outcomes of curricula for children with mild or single disabilities. An incomplete understanding of the unique characteristics and development of this population may also be an obstacle to the provision of interventions that would optimize their development.

Current research strands investigating characteristic fluctuating levels of alertness in children with SMD, new viewpoints on the appropriate outcomes of curricula, and the application of systems theory to child development may lead to improved interventions for this population. Direct care providers of children with SMD have noted that their students often do not exhibit the prolonged periods of attentive and engaged behavior necessary for observing and learning from their surroundings. These poor levels of alertness may serve as obstacles to learning. Researchers have characterized these fluctuating levels of behavior as similar to fluctuating states of awareness exhibited by infants. This comparison has led to the body of research on the role these various levels of awareness, called behavior states, plays in the lives of children with SMD.

In addition to the potential promise of new insights into the behavioral characteristics of individuals with SMD, the reconceptualization of quality of life as a more appropriate outcome goal, rather than vocational or self-care skill goals has driven recent research on curricula. Definitions of quality of life, outcome measures, and interventions designed to increase these goals have been investigated. Measures to assess quality of life goals are being developed and investigated.

Theoretical frameworks have evolved in developing interventions for this population. Guess (2000) identified the application of system theory to frame research involving children with SMD as one of the most promising developments in the future of interventions.

Research that is framed within these themes may contribute to the discovery of effective interventions that address some of the dissatisfactions reported by caregivers and direct care providers. The dissatisfactions of lack of time to implement interventions and lack of impact that interventions seem to have in the lives of children with SMD continue to be expressed. As currently conceptualized, an effective intervention is one that directly impacts the quality of life of the child and can be delivered without disproportionate cost in terms of time by direct care providers. In addition, framing the evaluation of possible interventions in terms of systems development adds to the knowledge of development of children with SMD.

The potential of technology to improve the quality of life for individuals with severe multiple disabilities has also received attention by researchers (Ellis, 1997; Guess, 2000; Gutowski, 1996; Kinsley & Langone, 1995). The use of technology to gain access and control to the environment has been a continuing line of research that began several decades ago when interventionists and others realized the possibility of these tools (Behrmann & Lahm, 1982; Goldenberg, 1979).

Purpose of the Study

The purpose of this study was to investigate the effect of contingent auditory stimulation provided by movement sensor technology on three measures of quality of life in young children with SMD. The contingent stimulation was provided by a movement sensor linked to a MIDI sound synthesizer. The movement sensor provided an immediate auditory response to any movement initiated by the child. The effect of this immediate auditory response on behavior state, happiness indices and amount of voluntary movement was investigated.

Need for the Study

This study addressed several areas of investigation pertinent to improving interventions for children with SMD. By framing investigation within a systems framework the study addressed the need to: (a) identify possible factors that affect behavior state organization in young children with SMD; (b) empirically evaluate a device that has been marketed as an appropriate intervention for this population; and (c) evaluate an intervention that does not require extensive training and time requirements by direct care providers.

Information about the effects of use of movement sensor technology on quality of life factors could be used to benefit the population of over 112,000 students who receive services in the category of multiple disability in the United States (National Information Center for Children and Youth with Disabilities, 2002) and their direct care providers.

Behavior state is an important area of research for students with SMD. The construct of behavioral state and its impact on the quality of lives of children with SMD has been identified as an important area of research (Arthur et al., 1995; Guess, 2000; Reid, Phillips, & Green, 1991; Richards & Sternberg, 1994). Studies such as this one that attempt to identify important factors are needed to further the understanding of behavior state.

Advances in computer technology have offered new opportunities to the population of SMD children but also challenge the interventionist to select appropriate and effective applications from an expanding list of possible systems. The commitment of financial resources to new technologies can be substantial. Empirical evaluations of the use of new technologies with this population, such as this study, are essential to justify the purchases and implementation of new technologies (Fields, 1999; Mount & Cavet, 1995). Especially important is the investigation of technologies that may offer young children the means to exert control over their environment as the experience of this control may be foundational to later learning (Brown & Cohen, 1996; Guess, 2000).

The costs of an intervention in terms of time, as well as finances committed to equipment should be considered, as lack of time has been identified by caregivers and direct care providers as an obstacle to the implementation of interventions.

Research Questions

Three research questions will be investigated in this study.

1. Is there a difference in the behavioral state organization of a young child with severe multiple disabilities across three conditions: (a) a typical play environment; (b) the same play environment with the addition of auditory stimulation contingent to the child's movements; and (c) the same play environment with auditory stimulation provided noncontingently?

2. Within intervals where the child is observed in an alert or interactive behavioral state, is there a difference in the percentage of intervals where a happiness index is displayed across the three experimental conditions?

3. Within intervals where the child is observed in an alert or interactive behavioral state, is there a difference in percentage of intervals in which the participant displays a voluntary movement?

Operational Definitions

Severe Multiple Disabilities

The functional definition of severe multiple disability used in this study is individuals who: (a) have severe motor limitations; (b) have sensory loss or functional sensory impairments; (c) are non-verbal; and (d) receive interventions at a basic sensory input level (Guess et al., 1990).

Behavior State

Behavior state refers to a construct of a level of awareness and ability to interact with the social and physical environment first identified in infants. The behavior state scale used in this study includes eight distinct states; sleep, drowse, awake/inactive/alert, interact, stereotypy, crying/agitated and aggression/self injury (S. Roberts, personal communication, April 3, 2002).

Preferred State

Two of the behavior states described above, awake/inactive/alert and interact, are designated as preferred states. Preferred states are behavior states that are presumed to be the most conducive to learning.

Behavior State Organization

Behavior state organization refers to how state manifests itself in the lives of individuals. The organization of state refers to the relative percentages of time that the individual spends in each state, how often the individual changes state, and how clearly the states are defined in the individual. Five attributes of state have been reported; quality (time in preferred state), stability, sequence patterns, cyclicity, and periodicity (Roberts, 1992). The attribute examined in this study was state quality or percentage of time in the preferred states.

Happiness Indices

Indices of happiness have been proposed as a way to measure the construct of personal happiness (a quality of life indicator) in individuals with severe multiple disability. A happiness index is any facial expression or vocalization typically considered to be an indicator of happiness among people without disabilities. Examples include smiling, laughing, and yelling while smiling (Green & Reid, 1996).

Voluntary Movement

Voluntary movement is defined in this study as movement of a body part that the participant's caretakers report that the participant is able to control.

Overview of Methods

The research questions in this study were investigated using a single subject multiple baseline design with 2 participants. The participants were children with SMD, aged 4 and 6 years, who live in southern Michigan. A total of 39 20-minute sessions were conducted in the participants' homes over a 13-week period. All sessions were videotaped. The contingent auditory stimulation provided in the intervention phase was generated by a movement sensor that translated any of the child's movements into musical phrases produced by an electronic keyboard.

In the baseline (A) phase of the experiment, the child was seated in her wheelchair with access to a typically provided play or leisure activity. In the first intervention phase (BC), the sensor emitter was placed near the child and was activated by the child's movements, providing contingent auditory feedback. The emitter was aimed at the area of the body over which the child had voluntary control. In the next phase (B) the sensor emitter was placed in view of the child but was activated by the investigator, providing auditory feedback that was not contingent on the child's movements. In the final (BC) phase control of the auditory feedback was returned to the child by placing the emitter near the child.

For Research Question 1 on the effect of the intervention on quality of behavior state, an observational protocol was used to record the number of observed 5-second intervals in each of the eight state categories. The researcher coded all of the sessions as they progressed. The percentage of intervals that the participant was observed in a preferred state was compared across the phases.

For Research Questions 2 and 3, videotaped intervals when the participant was identified as being in one of the preferred states were transferred from the master video tape to a second videotape for analysis. The researcher viewed and coded these videotapes in random order at the conclusion of the experiment. The data for Research Question 2 on the effect of auditory contingent response on enjoyment of the activity consisted of percentages of preferred state intervals during which the participant exhibited a happiness index.

Data for Research Question 3 on the effect of auditory contingent response on amount of voluntary movement consisted of the percentages of preferred state intervals during which the participant exhibited a voluntary movement

Data points for all three questions were graphed for visual analysis. A descriptive statistic of effect size, ***d***, which is calculated by dividing the difference in means of adjacent phases by their pooled standard deviation, was used as an adjunct to visual analysis.

Limitations

All single subject designs have limited external generalizability. Statistical generalization from a sample to a target population is not possible because of the non-random selection of the participants and the non-independence of the scores. Decisions about generalizability must be made rationally, rather than from statistical inference and these decisions depend on the internal validity of the experiment.

Internal validity is more likely to occur when experimental conditions are controlled enough so that the change of experimental conditions rather than other simultaneously changing factors can be posited as the cause of any change in the dependent variables being measured. Unfortunately, there were many factors such as antecedent conditions and the participants' health status that were not closely controlled in this experiment.

One source of variability has to do with the characteristics of SMD. Children with SMD have a very high incidence of illness and health problems. Although both participants completed all of the sessions, there was no control for daily health condition of the child which is a potential source of variability.

A second major source of possible variability resulted from difficulty in standardizing the conditions under which the experimental sessions were conducted in the participants' homes. The sessions were conducted with varying levels of background noise, interactions with siblings and parents and with slightly different placement of the child's wheel chair relative to the experiment. These conditions could not be completely controlled in the natural settings of the home environment. Antecedent conditions such as changes in schedules due to school vacations, snow days, doctor's visits and medical treatments are also part of the fabric of the lives of these children and could not be completely standardized.

In addition to variability issues, the fact that only two children participated in the study limited the opportunity for replications of any effect in this study. More participants would have strengthened the internal validity of any conclusions.

Internal validity is also related to the construct validity of the measures used to evaluate the outcomes. The three measures used in this study, behavior state, happiness indices, and amount of movement are emerging assessments. Further study and evaluation of the construct validity of these assessments may be necessary as they are used by different researchers in a variety of settings.

CHAPTER 2

Review of the Literature

This chapter will provide a review of: (a) the characteristics of students with severe multiple disabilities (SMD); (b) the theoretical perspectives that have been used to inform interventions targeted to this population; (c) the curricula that have been implemented for this population over the past few decades; and (d) the provision of contingent stimulation as an intervention strategy.

Characteristics of Children with Severe Multiple Disabilities

With the passage of universal access to education laws in the mid-1970's, children in the United States who met the criteria delineated in one of 12 categories of disability became entitled to special educational services. This legislation (PL 94-142) ensured the right of education to virtually all children no matter how severe their disabilities.

The category of multiple disability was created to include children who had more than one disability. The federal government defined children in this category as "those students who have concomitant impairments, other than deaf-blindness, such as mental retardation-blindness, mental retardation-orthopedic impairment, etc., the combination of which causes such severe educational problems that they cannot be accommodated in special education programs solely for one of the impairments" (U.S. Department of Education, 1995).

This definition acknowledged the fact that the effects of more than one disability are multiplicative; that is, the effects of one disability interact with the effects of the other disability so that the multiple disability has a different and unique effect on development than any of the disabilities in isolation (Brimer, 1990). Children who meet the criteria for this category exhibit a wide range of abilities and educational needs. A continuing frustration expressed by educators and stakeholders was the lack of functional definitions for various subgroups of these students, particularly those who could be categorized as having the most severe and profound disabilities. This particular subgroup of students has provided special challenges to direct service providers over the past few decades (Ferguson, 1985; Izen & Brown, 1991; Rainforth, 1982; Sailor et al., 1988; Sternberg, 1988).

There is no universal consensus on the educational definition for the subgroup of students with SMD (Ferguson, 1985; Siegel-Causey, Guy, & Guess, 1995). Several functional definitions have been proposed (Dewson & Whitely, 1987; McDonnell, Hardman, McDonnell, & Kiefer-O'Donnell, 1995; Orelove & Sobsey, 1987; Reid et al., 1991). Proposed defining characteristics of students with SMD have included: (a) cognitive abilities (when testable) with a mental age of less than one year; (b) sensory impairments; (c) severe physical impairments with no ambulation; and (d) dependence on others for all physical needs. Individuals with SMD usually are non-verbal and often display only minimal responsiveness to visual, auditory and olfactory stimuli.

Historically, children and individuals in this subgroup of disability have made up a significant proportion of the populations of institutions where they received custodial care. Changes in social mores in the 1960s and 1970s contributed to the community normalization movements as well as efforts to de-institutionalize service to this and other previously disenfranchised populations. Debate on whether students with SMD should have access to educational services (Kauffman & Krouse, 1981) was resolved with court action (Baer, 1981) that reaffirmed the intent of legislation was to provide universal educational access regardless of the severity of the disability.

In recent years an increasing number of children with SMD receive educational services in their home communities and schools. However, despite advocacy for inclusion in regular education classrooms (Downing, 1996; Hanline & Fox, 1993; Jorgensen & Calculator, 1994), the majority of children with SMD continue to receive education in segregated classrooms and facilities (Wisniewski & Alper, 1994).

Individuals with SMD need lifetime care and support in all areas of life. These outcomes are quite different than the typically developing child or the child with mild to moderate disabilities and thus have presented educators with the difficult task of selecting appropriate educational curricula. Curriculum, by definition, includes both instructional methods and goals (Noonan & McCormick, 1993). Curricula generally address two components of instruction, "how to teach" and "what to teach." Two theoretical perspectives on child development; behaviorism and constructivism, have influenced the development and implementation of instructional methods, the component of "how to teach" for this population.

Child Development Theories

Behaviorism

Early attempts to change the behavioral repertoires of individuals with SMD were based on operant conditioning paradigms. Researchers demonstrated that individuals with SMD could increase the frequency of certain behaviors in response to a contingent stimulus (Haskett & Hollar, 1978). Bijou (1981) credited the use of behavioral techniques with improving teachers' attitudes about the learning potential of children with a range of disabilities.

Increasing observable positive behaviors or extinguishing undesirable ones was the focus of much of the behavioral research on persons with SMD through most of the

1970's (Guess, 2000; Reid et al., 1991). Research in behavioral frameworks included investigations on the relative efficacy of different reinforcement schedules, evaluation of strategies to teach generalization of skills, and identification of effective reinforcers.

In a comprehensive overview of behavioral research that was conducted between 1949 and 1982, Reid et al. (1991) reviewed 39 studies that had the goal of teaching adaptive skills or improving postural control to individuals with SMD. They defined adaptive skills as behaviors that allow an individual to take some degree of care of himself or herself, express his or her wants or needs, participate to some extent in remunerative work, function similarly to persons without disabilities in regard to use of leisure time, or participate in community experiences.

They reviewed 13 studies conducted between 1949 and 1979 that demonstrated discrete behaviors such as pressing a lever, raising an arm, vocalizing, or pulling a ring could be increased when reinforcers such as edibles, vibration, or music were applied contingent to exhibition of the target behavior by the individual with SMD. Six studies conducted between 1975 and 1982 focused on improving the participant's postural control (holding the head up) by reinforcing this target behavior with music, cartoons, or verbal praise.

Twenty studies conducted in the late 1970s and 1980s targeted a variety of behaviors such as eating skills, social and communication behaviors, fine motor skills, and manipulation of leisure materials. Some behavior change was reported in all of the studies, although not with all of the participants. Reid et al. (1991) reached two conclusions in their review. They concluded the reviewed studies had not demonstrated that persons with SMD could acquire any independent adaptive skills, as the studies did not report the generalization of the targeted skills to different situations. The authors also noted that the one-to-one client ratio used to conduct the training in the studies might be too time consuming for implementation in actual practice.

Behaviorist interventions continue to be used with individuals with SMD (Lancioni, O'Reilly, Van Dijk, & Klaase, 1998; Silliman-French, French, Sherrill, & Gench; 1998) to increase or decrease specific behaviors. Instructional textbooks for pre-service teachers (Alberto & Sharpton, 1988) provide information on task analysis, reinforcement schedules, and reinforcer selection. Although behaviorist interventions have been used effectively, not all students appear to benefit from this approach. If the targeted behavior does not change the individual's ability to communicate or functionally do anything, it can be argued that increasing that behavior does not appreciably improve the individual's life. It may also be difficult to use a behaviorist intervention when an appropriate reinforcer for the individual with SMD cannot be identified (Ivancic & Bailey, 1996).

Constructivism

Constructivist perspectives are based on Piagetian and neo-Piagetian concepts that learning and cognition are the result of children's interactions with the physical and social environment. These perspectives assume that children are intrinsically well equipped for actively developing cognitive and social understandings through physical interaction with their surroundings.

Current best practices in early childhood education of typically developing children are heavily influenced by these constructivist, action based theories of learning and development (Bredekamp, 1993; Fox, Hanline, Vail, & Galant, 1994; Mallory, 1992). In constructivist frameworks, a significant role of the early childhood teacher is to present typically developing children with frequent opportunities to interact with objects and people (Fox et al., 1994). Teachers are encouraged to provide children with a choice of stimulating toys and materials that are accessible for child directed play. Instructional targets are often based on child interests and initiations.

This view of the child as an active learner is seldom used to explain the behaviors of children with SMD, primarily because of their limited abilities to engage in interactions with the environment (Carta, Schwartz, Atwater, & McConnell, 1991). This limited ability to engage in interactions results in a more directive role for the direct care provider in prompting and mediating interactions with the environment. Rather than basing instructional targets on the SMD child's interests, the interventionist often selects the instructional goal.

However, some interventions for children with SMD within this framework have been investigated. One approach is to make features of the physical environment more accessible to the child. The importance of a suitable and accessible physical environment has been emphasized both in educational considerations for typically developing children (Mallory, 1992) and children with disabilities (Hanline & Fox, 1993; Schneekloth, 1989). Modifications to the physical environment for children with SMD have included stabilizing objects and playthings very close to the children so that even small motor movements will allow the children to engage in continued contact with these objects.

Specialized environments such as a "playpen" (Landesman-Dwyer & Sackett, 1979), a "Little Room" (Nielsen, 1991, 1992), and an "activity box" (Dunnett, 1999) have been developed and investigated by researchers guided by this framework.

In the Landesman-Dwyer and Sackett (1979) study, the investigators were interested in increasing the variety and complexity of behaviors exhibited by their participants, aged 2-20 years who were residents in a state school and totally dependent on others for care. The researchers constructed two square "playpens" that had open tops and eight interchangeable panels for sides. The playpens contained stimulating objects such as strings of multi-colored balls, ticking metronomes, pillows filled with scented materials, mirrors and squeeze toys. Eight of the participants received an experimental treatment that consisted of sessions in the playpen. The participants in the experimental condition were positioned in the playpens for 30 minutes daily in an upright or elevated position, either by themselves or with a peer over a period of four to five months.

Landesman-Dwyer and Sackett (1979) investigated the effect of the experimental treatment on three dependent variables: (a) organization of sleep and active states; (b) behaviors such as shifts in body position, touching objects, vocalizations, looking behaviors, mouthing, facial expressions, and head movements observed in the participants; and (c) test scores on the Bayley Scales of Infant Development.
Results were that the participants in the experimental condition increased their vertical head movements, looking and touching behaviors and time where they demonstrated activity increased. Bayley scores did not improve.

Nielsen (1991, 1992) also constructed a specialized play area she called the "Little Room" for participants in her investigation. The Little Room was constructed of pipes that held three side panels constructed of various materials and Plexiglas top and was placed over the participant who was lying on his or her back. Various objects were attached to the top with elastics and were arranged to hang near the face and hands of the participants who were placed in the Little Room on their backs. The goal of her investigation was to see if exposure to this play area facilitated the development of the concept of object permanence. Nine of her 20 congenitally blind participants (aged 8-16 months) had additional disabilities of mental retardation, and of those 9, 3 participants had cerebral palsy. The participants were placed in the Little Room or a control environment (consisting of just the frame of the room, without the panels) for eight 20-minute sessions for four to five days.

Nielsen (1991) found that the total number of contacts with the toys and objects made by many of the participants increased, as did the complexity of their movements. She suggested that the receipt of the same feedback over and over again (as the objects returned to their positions after being released) helped the participants learn to locate specific objects. She also speculated that the absence of sounds interfering from the outside environment while the child was enclosed by the sides and ceiling of the Little Room facilitated the participant learning to connect his or her activity directly with the sound it produced. Many direct care providers have constructed similar play areas that have walls to cut off outside sounds and provide a variety of tactually interesting objects near the child (Dunnet, 1999).

The constructivist emphasis on the child's physical interaction with the environment as the foundation of cognitive development is based on observations of typically developing children. This template of development may not be applicable to the development of individuals who have disabilities that prevent these physical interactions. Some individuals with severe physical disabilities who produce little or no voluntary movement since birth have been able to demonstrate normal cognitive and communicative abilities when provided with augmentative communication (Berninger, 1988; Eagle, 1985). Thus, physical interaction with the environment may be only one of several possible routes to cognitive competence.

Interventions based on constructivist approach have the advantage of not requiring the time intensive one-to-one teacher-student ratios that are often needed to implement behavioral training routines. An attractive feature for direct care providers is that such an environment allows children with SMD to "experience 'things'" without adult help or intervention (Dunnet, 1999).

Systems Theory

Systems (also called chaos, non-linear and dynamical system) theory is a conceptual framework that has come to dominate the thinking in the biological and physical sciences. Systems theory posits that all natural entities are composed of multiple and diverse parts or sub-systems that combine in various ways to produce coherent and patterned behavior. All entities are conceptualized as self-organizing themselves in various ways and according to various timetables. The emerging patterns of organization or development are not following a pre-determined and innate hard-wired plan, but rather emerge in response to the context or subsystem timetables that exist within the entity.

Systems theory has been applied to such diverse phenomena as the development of tornadoes, mineral crystal development, the evolution of social organizations and development in human beings. The pattern of development has been described both through mathematical modeling and the use of analogies. Systems theory has been applied to the study of motor development in young children (Thelen, 2001), development of communication skills (Fogel & Thelen, 1987), and cognitive development (Lewis, 2000; Thelen & Smith, 1994; van Geert, 1991).

Some major tenets of systems theory are: (a) joint determination by multiple causes; (b) context sensitivity and contingency- the significance of any one cause is contingent upon the state of the rest of the system; (c) development as construction; and (d) distributed control- no one type of interaction controls development (Oyama, Griffiths & Gray (2001).

One tenet of systems theory when applied to human development is the assumption that cognitive, social/emotional, and physical development is the result of various diverse parts of the system interacting and organizing in response to both internal factors and environmental or external factors. According to systems theory, a biological organism seeks a stable pattern of organization that is optimal for that place and time. These preferred states of stability are called attractor states in systems vocabulary (Ennis, 1992; Fogel & Thelen, 1987). Attractor states can be described as shallow (easily perturbed or reorganized) or deep (typical states of functioning if the system is undisturbed). As different subsystem components are scaled differently (have different time tables) a change in one component can move the system toward instability. This instability may move the system out of a shallow attractor state into a new level of performance or stability.

The subsystem components that appear to change the pattern of the system are called control parameters. Different subsystems can serve as control parameters at different times as the system is re-organizing (Fogel & Thelen, 1987). Control parameters can be within the system (endogenous) such as current chemical balances in the blood, or external (exogenous) to the system such as the availability of nutrition or social support. With the myriad of existing endogenous and exogenous parameters, it often difficult to determine exactly which component is contributing to the development of new patterns (van Geert, 1991).

It is during these periods of relative instability that qualitative changes in the individual are presumed to take place. Some factors may act as catalysts to shift the entire system into new modes of organization. These times of instability are an essential characteristic of development (van Geert, 1991).

The framework of system theories may be an attractive lens through which to view the development of children with SMD. Two systems concepts, "equifinality" and the "cascade effect," seem particularly relevant. The concept of equifinality refers to the idea that there are multiple paths to competence. In motor development, for example, all intact babies gain the ability to walk, but not all gain this skill on the same timetable, by experiencing the same environments or child rearing practices, or by going through the same intermediate stages (Thelen & Smith, 1994).

The concept of cascade effect, sometimes called the "butterfly effect" when used as an example in weather systems, is the idea that small changes in initial conditions can produce larger changes at a later time. The effect of that initial difference may cascade through subsequent reorganizations of the system. As the knowledge about what these differences are increases, and as the ability to provide early interventions that affect these differences increases, the result may be an improved outcome for some children with SMD.

Another attractive component of systems theory is that it emphasizes that the organism cannot be studied apart from its environment. Thelen's studies of crawling and walking as forms of locomotion show that when different external control parameters exist, different types of locomotion may emerge. Thelen gives the example of a typically developing infant that she observed who never crawled but rather, but moved from place to place by scooting around her home's highly polished and slippery floors (Thelen, 1990).

The "solutions" that benefit the individual with SMD may be different from those that benefit typically developing individuals. For example, observable emerging communication competence in typically developing children may be babbling as a precursor to pronouncing appropriate words. However, in a child with SMD an observable emerging competence in communication might be head control in order to activate a switch for an augmentative communication device. Using the typical development template to target instructional goals in either behavioral or constructivist frameworks may be counterproductive to what is the best solution for an individual with SMD (McClennen, 1991; Mulderji, 2000.)

Some solutions that the individual with SMD exhibits may also appear counter-productive to what would be considered optimal development. For example, many individuals with SMD develop stereotypical behaviors that appear to interfere with other activities. However, these behaviors may fulfill a need for the individual that is unavailable through other means. In another example, patterns of learned helplessness are often described in these individuals (Basil, 1992; Finkelstein & Ramey, 1977; Robinson, 1986). Learned helplessness is described as an inability to complete an action even if it is possible because there is an expectation of helplessness (Abramson, Seligman & Teasdale, 1978) and is thought to result from early failures in attempting to engage with the environment. Learned helplessness is often described as a secondary handicap that prevents further attempts at engagement with the environment (Robinson, 1986), but it could also be considered reasonable adaptation by the individual who indeed, will not have much control.

As White (1980) observed when discussing goal setting for children with SMD, form should not be confused with function. If the ultimate function is locomotion for example, inappropriate concentration on walking (one form of locomotion) may be to the detriment of ultimately attaining the function.

The usefulness of systems theory as a research framework for possible interventions is still being explored. Oyama et al. (2001) write that developmental systems theory is not a theory "in the specific model that produces predictions to be tested against rival theories." (p. 1-2) Rather, it can be considered a general theoretical perspective on development.

Systems theory has been applied to studies of the characteristics and possible interventions for students with SMD (Guess, 2000; Guess & Sailor, 1993; Guess & Siegel-Causey, 1995). Studies conducted in this framework would ideally consist of longitudinal studies of individuals with enough measurements to describe periods of instability leading to growth and relative importance of possible control parameters during these periods of instability leading to higher levels of organization (van Geert, 1991). Single subject studies in which various parameters are manipulated have also been used to further knowledge within a systems framework. The challenge to researchers of interventions, then, is both to identify possible important control parameters during individual courses of development and manipulate them to determine if more optimal courses of development result.

History of Pedagogical Approaches

There is continuing debate about suitable goals for SMD students because many educational interventions have not appeared to make a significant difference in their lives (Snell, 1987). Students with SMD usually cannot be expected to acquire normalized types of behavior such as work skills or independent self-care skills that are the focus of curricula for students with no or mild/moderate disabilities. The question of the second component of curricula, "what to teach" has been revisited many times over the past few decades.

Developmental Orientation

Advocates of the developmental approach assumed that instruction should focus on helping students attain typical developmental milestones (Cohen, Gross, & Haring, 1976). The goal of educational intervention from a developmental perspective is to remediate a child's underlying cognitive and physical deficits. Instructional goals are developed from comparing the student's current level of performance to typical infant and early childhood milestones, and then teaching to the next skill generally attained by the typically developing child. Instructional materials are selected according to the developmental or mental age of the children rather than their chronological ages.

From a remedial standpoint it "makes sense" to follow a normal developmental template to select skills. Many self-care and functional skills are based on clear physical abilities or prerequisite skills. For example, the ability to chew and swallow solid food requires that the individual master prerequisite skills of tolerating the utensil placed in the mouth, demonstrating an adequate gag reflex to protect against choking, and the ability to make chewing movements.

However, individuals with SMD demonstrate so many deficits in all areas of life that remediation of all of them is not possible. The direct care provider may be overwhelmed by the sheer number of needs. Children with SMD may not be able to master one skill in the developmental sequence and could be trained endlessly on a single skill with no measurable benefit or mastery ever taking place. Another criticism of the developmental approach for students with SMD is the tendency to provide these students with objects that are not age appropriate. That is, some objects such as baby rattles might correspond to the child's developmental age but appear inappropriate for the child's chronological age.

Functional Orientation

Advocates of a functional orientation suggest that targeted skills should only be those that are needed for the child to function as an adult as independently as possible (Switzky, Rotatori, Miller, & Freagon, 1979). Brown, Neitupski and Hamre-Nietsupksi (1976) suggested a "criterion of ultimate functioning" rather than typical developmental progressions as the appropriate educational orientation. The interventionist using a functional orientation selects skills that will be the most useful to the student in the present or future environments (Holvoet, Guess, Mulligan, & Brown, 1980). The teacher first conducts a task analysis of functional skills (Browder, 1991) that will be needed in future environments. Then, they directly teach each skill or skill component (Orelove & Sobsey, 1987; Sailor & Guess, 1983; Wolery, Ault, & Doyle, 1992) and finally, link the components together into completion of the entire task.

When students are unable to acquire some of the skill components, teachers are still encouraged to teach the attainable components. Baumgart et al. (1982) called this procedure "partial participation." Partial participation was based on the premise that completing some skill components would help include the student in the activities of daily living. For example, a SMD child may not be able to remove her jacket, but her partial participation goal might be to raise her arms with a verbal cue to allow her caretaker to remove the coat (Ferguson & Baumgart, 1991).

As the main goal of functional orientation is to increase independence it may have little benefit for some SMD individuals who cannot functionally complete any tasks related to self-care or independence. Interventions may have increased some skills, but not enough to make a difference in the individual's daily life.

Quality of Life Orientation

When many functional goals may not be attainable, some experts suggest that the goals of intervention programs should target goals that are directly related to the individual's quality of life such as maintenance of existing behavioral repertoires, prevention of neuromuscular degeneration, and the provision of more enjoyment (Reid et al., 1991). There is emerging consensus that these "quality of life" goals are both more appropriate and attainable than developmental or functional goals for the SMD population. However, goals related to quality of life may prove to be more difficult to quantify than goals related to developmental progression or functional skills, as quality of life is a more subjective concept.

An individual's experience of quality of life depends on two aspects. The first aspect is the environment of the person and can be objectively measured. Questions such as "Is there food for the person to eat?" or "Does the person live in a low crime area?" can be answered objectively. The second aspect of quality of life is the individual's own subjective perception of his or her circumstances. Questions such as "Am I satisfied with my relationships" or "Do I like my work" can only be answered by that individual and may not be directly related to the objective measures. Most experts agree that both objective descriptors and subjective evaluations should be included in an assessment of a quality of life (Felce & Perry, 1995).

Researchers who focus on the quality of life of individuals with SMD assume that factors important to typically developing individuals are also important in the lives of individuals with SMD. Researchers have investigated ways to increase the student's tolerance of therapeutic and medical procedures (Green & Reid, 1999b) to increase physical comfort and provide freedom from pain. Researchers have investigated ways to teach the individual's choice making skills (Newton, Ard, & Horner, 1993; Reid, Everson, & Green, 1999) and ways to determine the SMD individual's preferences (Houghton, Bronicki, & Guess, 1987; Thompson & Martin, 1994). Researchers have also investigated ways to train appropriate communication partners for students (Brown, Gothelf, Guess, & Lehr, 1998; Downing, 1996; Kaiser & Goetz, 1993) in order to provide more opportunities for socialization.

Several researchers have focused on the aspect of choice as a particularly important aspect of quality of life (Brotherson, Cook, Cunconan-Lahr, & Wehmeyer, 1995). Everson and Reid (1997) noted that individuals with SMD often have very few opportunities to make choices on a day to day basis. Often, the direct care provider makes the choice for the individual with severe multiple disabilities (Bannerman, Sheldon, Sherman, & Harchik, 1990; Bedini, 1993).

Two strategies that have been used to identify preferences have been observing the individual's reactions to the activity or presenting two or more stimuli at the same time and prompting the participant to choose (Newton, Ard, & Horner, 1993). Everson and Reid (1997) point out that it is possible to ascertain choices made by individuals with SMD by observing the time that the individuals attends to certain activities or their behavioral indices that reflect enjoyment such as smiling.

An example study that informed the realization that opportunities for choice was limited was conducted by Houghton et al. (1987). The researchers observed 37 students aged 8.5-21 years in classroom settings. They observed whether staff responded to choices indicated by the children through body movements or vocalizations. For example if a child spit out a spoonful of one type of food, a staff response that commented on the child's dislike of the food and willingness to offer another would be scored a response to choice. Likewise, if the child began crying while positioned in one position, and the staff repositioned the child or offered a toy with the comment that the child didn't like the position would be scored a response. They recorded several hundred student initiations and reported that the staff responded to less than 20% of these initiations. The researchers suggested that this low of rate of response resulted from the emphasis on behavioral teaching paradigms. The emphasis on stimulus control techniques may have distracted the caretakers from observing and responding to student-initiated behavior.

Quality of Life Indicators

Behavior State

Teachers and researchers have noted that some students with SMD often appear to be non-engaged with their surroundings. At various times individuals with SMD appear drowsy, sleep at inappropriate times or engage in stereotypical behaviors which appear to interfere with attending to external input. Teachers often continue to implement their educational routines without regard to whether the child is attending to the stimulus presented.

Several researchers suggested that these varying levels of alertness observed in individuals with SMD might be comparable to the construct of behavior state described in the literature on typically developing infants (Rainforth, 1982; Simeonsson, Huntington, & Parse, 1980). The construct of behavior state in the infant literature has been well established. One of the basic tenets of infant state theory is that the child's ability to interact with and learn from her surroundings is optimal in certain alert states. Thus, it was suggested that the possible poor state control exhibited by individuals with SMD might interfere with their development and quality of life.

Behavior state in infants. The construct of behavior state in infants was first suggested by Wolff (1959). He noted that infants displayed periods of varying alertness and receptivity to their surroundings that ranged from deep sleep to alert activity. From his observations of typically developing infants, he identified the six behavior patterns (later called states) that he posited encompassed the range of the infants' receptivity to their surroundings.

Wolf's original taxonomy of states was expanded and refined by several groups of researchers according to their own preferences and scientific backgrounds (Brazelton, 1973; Brown, Leavitt, & Graham, 1976; Korner, 1972; Prectl, 1974; Thoman, 1990). States can range from deep sleep to alert /active and various proposed taxonomies describe varying numbers (typically around six) of discrete states between these two extremes. Examples of behavior scales that have been used in infant research are reproduced in Table 1.

There is general consensus on the general theoretical description of behavior state as a set a non- learned set of behaviors, which reflects the young infant's ability to react to and interact with environment and social variables.

Korner (1972) describes behavior states as qualitatively different conditions with distinct types of internal organization. The same external stimulus can provoke a different response in the young infant depending on the infant's current state.

Behavior state has been described as a distinct mode of neural activity and reactivity reflecting the condition of the nervous system (Prechtl, 1974), a gating mechanism (Thoman, Korner, & Kraemer, 1976) and the means through which the organism controls levels of stimulation (Brazelton, 1978). No consensus on the exact definitions and appropriate measurements for state has been reached. State has been

Table 1

Behavior State Codes Used in Research with Infants

	Campos & Brackbill (1973)
Quiet sleep	Infant's body appears relaxed muscularly. Eyes are usually closed.
Active sleep	Infant exhibits diffuse movements of relatively frequent occurrence. Some twitches, grimaces, smiles, sucks, occasional movements of the eyeballs are present.
Drowsiness	Infant exhibits fluttering of eyelids. Eyes, when visible have a glassy appearance. Frequent relaxation followed by sudden jerks.
Quiet awake	Infant displays little gross motor activity. The eyes are open and appear bright and shiny.
Active awake	Infant displaysconsiderable gross motor activity. Vocalizations are of the cranky, fussy variety.
Crying awake	The criteria is the same as active awake but accompanied by crying. Tears may or may not be present.
	Korner, Brown, Reade, Fernback, & Thom (1988)
Quiet sleep	Infant's eyes are closed and respirations are regular.
Active sleep	Infant's eyelids are mostly closed. Respirations are faster and more irregular than quiet sleep. Motor activity varies from slow limb movements to generalized body writhing. Grimaces and other facial expressions are frequent. Rapid eye movements are present.
Drowsiness	Infant is relatively inactive. Eyes are open but have a dull or glazed appearance.

Table 1, continued

Alert inactivity	Infant's face is relaxed, does not grimace, and the eyes are open and have a bright and shiny appearance. Body movements, if any, are slow and not vigorous.
Waking activity	Infant engages in vigorous or diffuse motor activity, frequently involving the whole body.
Crying	Infant exhibits crying vocalizations associate with vigorous, diffuse motor activity. The eyes may be open or closed.
Unclassifiable	Infant exhibits behaviors that do not clearly meet the criteria of any of the other states.

Colombo, Moss, & Horowitz (1989)

Deep sleep-A	Infant exhibits no movement except mouthing or startles. Deep, regular and slow abdominal respirations.
Deep sleep-B	Infant exhibits no movement except mouthing or startles. Respirations are more irregular and faster than Deep sleep -A but still deep and abdominal.
Active sleep	Infant exhibits facial movement during sleep. Respirations are costal, shallow, irregular and fast. Rapid eye movements may be present.
Drowsiness	Infant's eyes may be open but appear dazed. Slow facial and bodily movement may be present.
Alert inactivity	Infant's eyes are open and bright. Infant is quiet and inactive.
Waking activity	Infant displays generalized motor activity. Facial grimacing or grunting with brief vocalization or cry outbursts is present.

Table 1, continued

Sahni, Schulze, Stefansi, Myers, & Fifer (1995)	
Code 1	Infant's eyes are closed. There is a predominately flaccid appearance. Body movements are limited to startles.
Code 2	The infant makes small body movements. Motor activity includes slow intermittent writhing movements, frowns, smiles, chewing and sucking movements.
Code 3	Infant displays rapid eye movements. Body movements are similar to Codes 1 or 2. Eyes may occasionally open or close or remain briefly half-open.
Code 4	Infant displays wakeful behavior.
Code 5	Infant is crying.
Code 6	Infant is feeding.

measured by physiological measures such as heart rate and respiration (Prechtl, 1974) and by behavioral observations of characteristics such as activity level, amount of vocalization and eye movement (Brazelton, 1973; Korner, 1972).

The continuing disagreement on taxonomy, exact definitions, and appropriate measurement procedures may limit comparisons between various studies (Thoman, 1990) although there is general consensus that infants' interactions with their surroundings appear to be dominated by behavior state until three months of age. Estimates of time in alert states of infants younger than 3 months range from 11% to 21% (Columbo & Horowitz, 1987), although more time in alert state is correlated with the amount of time spent with the mother (Thoman, Davis, & Deneberg, 1987).

Alert state is a control variable in the majority of reports on perceptual and cognitive abilities in newborns and young infants (Ashton, 1973). It is difficult to elicit consistent responses from infant participants unless state is controlled. Researchers agree that the infant may be the most receptive to input from the environment while in one of the alert states (Thoman, 1990), and that achieving this state may be necessary for optimal learning to occur (Brazelton, 1978).

In addition to being a control variable, behavior state has been a dependent variable in a large body of infant research (Becker & Thoman, 1983; Boismier, 1976). Researchers have investigated both soothing strategies to facilitate sleep states and activating strategies to facilitate alert states. The relative influences of internal and external factors in the manifestation of state is a source of ongoing debate (Becker & Thoman, 1983).

State organization has also been investigated as a way to differentiate between typically developing and compromised infant populations. For example, Prechtl, Theorell, and Blair (1973) found that the percentage distributions and durations of various states in typically developing infants were different than atypical infants who had Down syndrome, jaundice, or cerebral functional disturbance. These state organization differences were described based on one six-hour polygraphic examination period conducted on the infants between the third and eleventh days of life.

Behavior state in individuals with SMD. Several researchers (Landesman-Dwyer & Sackett, 1978; Rainforth, 1982) questioned the possible influence of behavior state in the lives of individuals with SMD. Special educators and other direct service providers had noted that these students often exhibit levels of non-alertness or stereotypy that may interfere with their ability to benefit from educational interventions (Sailor et al., 1988) or that interfered with assessment (Richards & Sternberg, 1989). Rainforth (1982) questioned whether these periods of non-alertness and stereotypy could be comparable to the behavior states described in the infant literature.

The possible influence of behavior state in the SMD population has been investigated by researchers over the past two decades. Researchers have attempted to: (a) develop observational protocols to describe and quantify behavior state; (b) describe state organization in individuals with SMD; and (c) observe and investigate of possible relationships between state and internal/external characteristics of the individual and his/her environment.

At least four codes describing behavior state have been developed and used by researchers with populations of SMD individuals. These taxonomies are presented in Table 2. The four research groups that developed these taxonomies relied on pilot observations of observable behavioral indices to create their categories.

Table 2

Behavior State Codes Used in Research with Individuals with Severe Multiple Disabilities

Landesman-Dwyer & Sackett (1979)	
Sleep	Characterized by closed eyes, slower rate of breathing. Lack of responsiveness to the environment.
Low level of activity	No clear responses to the environment. Minimal peripheral movements of the body. Eyes are open.
Moderate level of activity	Represents the individual's moderate range of activity. Clear movements of some body parts.
High level of activity	Eyes are open and moving. Some vocalizations. Clear response to, or interaction with the environment.

Simeonsson, Huntington, Short, & Ware (1988)	
Deep sleep	Eyes closed, regular respiration, no movements.
Intermediate sleep	Eyes closed; few minor facial, body and/or mouth movements; respiration is periodic, alternating periods of shallow and deep breathing.
Active sleep	Eyes closed, irregular respiration, some gross motor activity (stirring, writhing, grimacing), mouth or other facial movements.
Drowsy	Eyes open and closed intermittently, fluttering eyelids, eyes have glassy appearance, frequent relaxation followed by sudden jerks.
Quiet awake	Relatively inactive, eyes open and appear bright and shiny respiration regular.

Table 2, continued

Active awake	Eyes open, diffuse motor activity of limbs and whole body, vocalizations of a content nature
Fussy awake	Eyes open, vocalizations of a fussy, cranky variety.
Mild agitation	Eyes open, diffuse motor activity, moderate crying, tears may or may not be present
Uncontrollable agitation	Screaming, eyes open or closed, tears may or may not be present
Richards & Sternberg (1992, 1993)	
Seizure	A seizure occurs within the interval.
Asleep	Eyes are closed. May be some movement and vocalization.
No orienting	Eyes are open but no eye movement. Motor movements are jerky or slight and non-purposeful.
Agitated	Awake. Vocalizing in a manner indicating discomfort or anger.
Arousal/ unclear	Eyes are open but not clearly focused on environment. May be voluntary movement but no purposeful interaction with any object or person.
Arousal/ orienting	Eyes opened and focused. May be gross or fine motor movements toward interaction with environment. May be changes in facial expression and/or vocalizations in response to environmental events.
Guess, Roberts et al. (1993), Guess, Roberts, Siegel-Causey, & Rues (1995)	
Asleep-inactive	Eyes are closed. Respiration is slow and regular. Body tone is relaxed.

Table 2, continued

Asleep-active	Eyes are closed. Respiration is uneven, may exhibit sporadic movements. May exhibit rapid eye movements, occasional facial expressions and or vocalizations.
Drowsy	Eyes are either open and eyelids appear "heavy," or eyes are opening and closing repeatedly. Vocalizations may occur.
Daze	No orientation to visual, auditory or tactile stimuli predominates. Few or no vocalizations.
Awake inactive-alert	Eyes are open. Some active visual or auditory orientation. Non-orienting body movements may occur. Vocalizations may occur.
Awake active-alert	Engages/interacts by making contact with a person or objects. Vocalizations in direct response to verbalized questions.
Awake active-stereotypy	Exhibits stereotyped behaviors (idiosyncratic, repetitive rhythmic movements of body or body parts).
Crying-agitated	May exhibit intense vocalizing, crying or screaming. Overall increased tension in body tone with accompanying agitation behaviors.
Seizures	Exhibits seizure behavior. The definition of seizure behavior is individual for each person and determined by direct care providers.

Landesman-Dwyer and Sackett (1979) conducted an early investigation that used behavior state as a dependent variable. They developed a four-category code of "levels of activity" which were sleep, low, medium, and high. They used this scale to describe the sleep- wake cycles of 16 participants for the duration of their study designed to test an intervention. The participants, aged 2-20 years old, were described as nonambulatory, profoundly mentally retarded, and unresponsive to external stimulation. Landesman-Dwyer and Sackett (1979) reported 94% agreement between two coders using percent agreement formulas.

The authors used the scale to compare the percentages of time that their two groups of participants spent in various states after 8 of the participants were exposed to an intervention designed to facilitate a higher level of alertness. From observations made over a 24-hour period they found that participants spent an average of 12.4 hours in the sleep state, 9.0 hours in low level activity, 3.1 hours in moderate level activity, and 2.0 hours in high level activity.

Richards and Sternberg (1992) developed a six-category scale of states from pilot observations of 7 participants they described as profoundly retarded, unable to perform self care skills independently, non-verbal, and nonambulatory. The six states they described were asleep, no orienting, agitated, awake/unclear, awake/orienting and seizure. Their protocol required 15-second observations for five-minute observation periods conducted both in the morning and afternoon in educational settings. They reported average interrater reliabilities of 87%, which were calculated by dividing the total number of agreements by the total number of intervals. Richards and Sternberg (1992) used this code to find possible correlations between endogenous and exogenous factors and existing behavior state in individuals with SMD.

Richards and Sternberg (1992) reported that participants spent approximately 13% of the time asleep, 14% of the time in the no orienting state, 5% of the time in the agitated state, 38% of the time in the awake/unclear state and 33% of the time in the awake/orienting state. No seizure activity was observed.

A nine-category taxonomy of behavior state is described in the Carolina Record of Individual Behavior (CRIB), an instrument for the assessment of developmental functioning of infants and children with disabilities (Simeonsson, Huntington, Short, & Ware, 1982). The researchers reported that they included state observations in the assessment protocol in order to document state influence on performance and because poor behavior state organization might be an early predictor of poor developmental outcomes. The evaluator using the CRIB documents the child's behavior state at the beginning and throughout systematic observations of the child's activities.

Guess and his colleagues have extensively documented the development of their behavior state code which has undergone several revisions. For two initial studies on observing behavior as reported in Guess, et al. (1988), the researchers adapted a behavior state scale from Brazelton (1973) that described six behavior states. The states were asleep/inactive, asleep/active, drowsy, awake/inactive/alert, awake/active/alert and crying/agitated. A pilot study was conducted with 11 students with SMD ranging from one to 19 years of age. All of the participants were identified as profoundly retarded with varying degrees of physical and sensory impairment. A momentary time-sampling procedure, that is, at 10-second intervals the observed behavior state was noted. Data were collected for 20 10-minute sessions conducted over 5 to 6 weeks.

A second pilot study involved 10 students aged 3-15 years. The same observational and recording procedures were used in this study with one exception. A 10-

second time interval procedure was used, that is the most prevalent state during the 10-second interval was recorded. Two coders rated 25% of the sessions in both studies and mean interrater reliability was reported at 90 and 93%, for the first and second studies, respectively. The researcher reported mean percentages of time in behavior states (averaged between the two studies) of approximately 14% of time in the two sleep states, 11% of the time in the drowsy state, 45% of the time in the awake/inactive/alert state, 20% of the time in awake/active/alert and 7% of the time in crying/agitated.

In later studies (Guess et al., 1990; Guess, Roberts et al., 1993; Guess, Siegel-Causey et al., 1993) the researchers amended their scale to include two new categories; stereotypy and daze. These new states were added to the original code to better describe behavior states that the researchers observed in this population.

Guess, Roberts, et al. (1993) observed 66 participants for one 5-hour period. The participants ranged in age from 20 months to 21years and were described as: (a) having severe motoric limitations; (b) were not responsive to the environment; (c) were nonverbal; and (d) received intervention implemented a basic, sensory level. In this study, a similar overall percentage agreement (93%) between raters was reported.

The behavior coding scale was subsequently expanded to 13 categories that included two subcategories of awake/alert/inactive and two-subcategories of stereotypy (Guess, Roberts & Rues, 2002). The most recent modification of the scale describes eight state categories that will be used in future research (S. Roberts, personal communication, April 3, 2002). This scale is reproduced in Table 3.

The meaningfulness of the construct of state and the ability to reliably measure and report it has been questioned by Mudford, Hogg and Roberts (1997). They reported that they were unable to replicate the interobserver reliability ratings that had been reported in the Guess et al. research. Mudford and his colleagues reported that obtained within-state reliability scores when they attempted to replicate use of the 13-category scale with 3 participants who had profound mental retardation. In a second report, Mudford, Hogg, & Roberts (1999) reported low agreements when five observers used the thirteen category scale to score videotapes of 2 participants, with a 15 minute section of tape for developing the consensual analysis. Mudford et al. (1999) recommended training to criterion of 80% agreement on the occurrence of each component (state) of the scale as a more stringent criterion for future researchers.

Guess and his colleagues responded that training procedures need to be carefully implemented and that coding should not be done from videotapes (Guess, Roberts, Behrens, & Rues, 1998; Guess, Roberts, & Rues, 2000). The Guess research group also maintained that their current eight-category protocol (rather than the 13-category one used by Mudford and his colleagues) would yield more acceptable reliabilities. Guess and his colleagues have concluded that behavior state could be reliably measured when observers received appropriate training and coding is done where the coder can closely observe the participant in the live setting. They have developed extensive training procedures (Guess et al., 1990) as well as a multi-media project reported by Bashinksi (1996) to train observers who are both researchers and direct care providers (Ault, Guy, Guess, Bashinksi, & Roberts, 1995; Guy, Guess, & Ault, 1993).

The four codes developed to describe behavior state in individuals with SMD have been used for various research agendas. Research has been conducted to describe state organization in individuals with SMD, evaluate the effects of an intervention on behavior state organization and identify possible factors that contribute to state organization. State organization refers to several attributes of state including the overall

Table 3

Current Behavior State Code

S. Roberts, personal communication, April 3, 2002

Sleep	Person's eyes are closed. Respiration can be slow, even or uneven. Motor activity may occur including characteristics such as mouthing, twitching, tossing and turning. Person may exhibit rapid eye movements (REM). Other behaviors may include occasional facial expressions (smiling, grimacing, frowning) and/or vocalizations (sighing, grunting, gurgling).
Drowse	Person's eyes are either open and eyelids appear "heavy," or eyes are opening/closing repeatedly. Vocalization may occur.
Daze	Non-orientation to visual, auditory, or tactile stimuli predominates. If person's vision is intact, eyes are open and appear glassy, dull and immobile. Motor movements (that are not orienting) may occur such as brief limb/body movements, startles. Respiration is regular.
Awake/inactive/alert	Person's eyes are open and responsive to visual or auditory stimuli. Visual activity may include tracking, orienting/focusing on stimuli, turning head, eyes looking towards stimuli. Occasionally eyes may be closed, but displays other signs of orientation such as smiling, learning toward, head turning. Non-orienting movements may occur (brief limb/body movements, startles). Demonstrates regular respiration. Vocalizations may occur.
Interact	Person engages/interacts/manipulates by making contact with a person or objects. Body movements to avoid stimuli or interaction (pulling away from someone). If person's vision is intact, eyes are open, bright, and focused. Visual, auditory, or tactile interactive patterns are exhibited with distinct fine and/or gross motor movements.
Stereotypy	Person exhibits behaviors that are stereotypical (idiosyncratic, repetitive rhythmic movements of body or body parts). Movements may include repetitive touching or

Table 3, continued

	movements such as head weaving, rocking, mouthing hand or objects, teeth grinding, arm and finger flapping.
Crying/agitated	Person may exhibit intense vocalizing, crying or screaming. Grimacing and/or frowning may occur with or without intense vocalizations or crying. Respiration may be irregular and eyes may be open or closed. Overall increased tension in body tone with accompanying agitation behaviors (intense vocalizing, facial expressions, crying).
Aggression/self injury	Person exhibits aggressive behavior toward self or others, which may include hitting, biting, pinching, etc. Behavior may be accompanied by intense vocalization/screaming or overall increased tension in body tone.

percentage of time spent in various states and the frequency at which an individual changes state. An important finding was that individuals with SMD generally exhibit organization patterns that are not optimal for learning; patterns that include a relatively large proportion of time in non-alert states and frequent changes between states. Guess et al. (1990) averaged the percent occurrences for each state across 50 students with SMD who were observed in educational settings. As a group, they spent 42% of the time in states that are not optimal for learning. Myers (1990) found that four preschoolers with SMD spent an average of 28% of the time in non-alert states over the course of three 55-minute observation sessions in inclusive educational settings. For comparison, she also observed four classmates matched for age and gender with the children with SMD. The typically developing children averaged about 10% of the time in non-alert states.

Another finding was that groups of individuals could be grouped by profiles that represented similar state patterns (Guess et al., 1990, Guess et al., 1991; Guess, Roberts et al., 1993; Guess, Roberts, et al., 1995). Table 4 lists these descriptive profiles. Two aspects of these profiles were significant. One aspect was that the total population percentages were similar across studies. In other words, a cross section of participants in each of four studies yielded similar proportions of participants in each profile.

A second aspect was that these proportions were similar for all age groups. In other words, these less than optimal profiles do not appear to improve with age as similar percentages were found across three age groups. In one study, (Guess, Roberts, et al., 1995) the profiles of 66 students were described. When the student profiles were compared by three age groups; 20 months-7 years, 7.5-12 years, and 12.5-21 years, there was no difference in the percentage occurrences of the profiles. In addition, a

Table 4

Descriptive Profiles of State Organization in Individuals with Severe Multiple Disabilities

Profile	Descriptions
1	Individuals who spend 75% or more time in preferred states
2	Individuals who spend at least 75% of time in preferred states but less than 20% of that time interacting with the environment
3	Individuals who spend less than 75% of time in preferred states, often exhibit stereotypy or crying/agitation
4	Individuals who spend less than 75% of time in preferred states, often exhibit sleep, drowse or daze
5	Individuals who do not fit into the above profiles but display a large number of states

series of observations of eight children with SMD from birth to age 4 years, Guess, Roberts, and Rues (2001) found that the typical non-optimal behavior state patterns or profiles stabilized for these children around the age of 3 years.

The ability to reliably assign students to these general profiles was also obtained in a study of five individuals conducted by Richards and Sternberg (1993). They used a using a different state classification scheme of five states but found that they could reliably assign students to these profiles.

In addition to large proportions of time in non-alert states, individuals with SMD were observed to change state quite often which may have implications for their ability to benefit from any orienting responses that they do display in alert states. The 25 participants observed in classroom settings in a study by Guess, Roberts et al. (1993) shifted states an average of 1.28 times per minute over a five-hour observation period.

Poor state organization has been described as a characteristic of individuals with SMD, an indicator of poor quality of life, and as an obstacle to learning. If individuals cannot maintain an appropriate level of alertness, they have diminished opportunities to maintain orienting behaviors and therefore benefit from environmental input.

Behavior state researchers have sought to identify factors that are associated with state organization in individuals with SMD. The construct of state has been considered within systems framework (Guess & Siegel-Causey, 1995). The task has been to identify both internal and external factors interact to result in behavior states. Although it is the interaction of both of these factors that result in the manifestation of certain states, certain parameters serve as control parameters in that they have the most amount of influence on the system at a given point in time. For example, it has been suggested that some combination of chemical or physical anomalies associated with the physical syndromes of Lesch-Nyhan, Cornelia de Lange, and Rett syndromes results in the high incidence of stereotypy observed in individuals with these syndromes.

Other internal factors may be more influenced by environmental interactions. For example, children with SMD often have feeding difficulties resulting from poor oral motor control or gastrointestinal disorders. Feeding difficulty can result in low calorie intakes and poor nutritional status (Ault, Guy, Rues, Noto, & Guess, 1994). Children with seizure activity require medications that have side affects of drowsiness. Poor nutritional status and some medications are associated with excessive drowse and sleep states in some children with SMD (Ault et al., 1994).

Several studies have been conducted to look for correlations between possible external factors and state in individuals with SMD (Guess et al., 1990; Guess et al., 1995; Guess, Roberts et al., 1993; Richards & Sternberg, 1997). Environmental variables that have been investigated for significant correlations with state include body position, presence of social contact, ambient temperature, surrounding activity levels, time of day, and presence of materials (Guess et al., 1995; Richards & Sternberg, 1992). Of these, only two variables, position of the student and the presence of social contact, have been consistently and significantly correlated with alert states.

Happiness Indices

One important component of several measures of quality of life is the concept of personal happiness (Felce & Perry, 1995). Personal happiness is a subjective construct often quantified by self-report when measured in populations of typically developing individuals. As happiness is related to, but is not totally dependent on, objective measurement of one's life circumstances, subjective scales are considered the most appropriate way to quantify this concept. Subjective scales are more challenging to construct for individuals who are non-verbal and non-mobile. The emerging importance of considering all aspects of quality of life for individuals with SMD has focused attention on the development of appropriate measurements of happiness for this population.

Research has centered on behavioral manifestations of emotions called indices of happiness. One main goal of this research has been to construct and validate an observational protocol that then could be used to measure outcomes of interventions designed to increase happiness.

Green and Reid (1996) reported an early attempt to quantify happiness in individuals with SMD. Their six participants were 18-41 years of age. The researchers selected observable responses generally associated with the expression of happiness. They defined happiness indices as "any facial expression or vocalization typically considered to be an indicator of happiness among people without disabilities including smiling, laughing and yelling" (Green & Reid, 1996, p. 69).

In this initial study they used a 10-second partial interval recording procedure. The specifics of observer training were not described other than directions to the observers that recording an index should only be done if they were certain they observed the index. Forty two percent of the sessions were rated by two raters and overall agreement was 98%. An agreement was scored if any index of happiness was noted during the interval.

In addition to demonstrating acceptable interobserver reliability of observations, the researchers sought to validate the relationship between observed happiness indices and actual personal happiness in two ways. First, participant videotapes were rated by two groups of practitioners, one unfamiliar with the participants, the second, the participants' direct care providers, on how happy the practitioners perceived the participant to be. These ratings were compared to the formal count of happiness indices and were found to be highly positively correlated.

The second method of validation was the comparison of the number of happiness indices exhibited by each participant during previously identified preferred activities of the participant versus those exhibited by the participant during his or her least preferred activities. Increased levels of happiness indices were noted during sessions when the participant was presented with preferred activities.

A similar method was used by Favell, Realon, and Sutton (1996). They videotaped 7 participants with SMD during recreational activities and had five college students (no explanation of their training procedures other than it lasted less than 30 minutes was reported) observe the video tape and record occurrence or non-occurrence of the happiness index in a 10-second interval. The indices count was then correlated with judgments of happiness reported by two direct care providers who worked with the clients. The validity of facial expressions, especially smiling as an indicator of happiness, was supported by the high correlations between smiling and independent staff ratings of happiness.

The researchers in both studies concluded that measuring happiness indices might provide one of the few methods available for evaluating programming for people who have difficulty demonstrating functional effects of reinforcement. These observational procedures were used in subsequent studies to evaluate interventions to increase happiness indices (Green, Gardner, & Reid, 1997; Green & Reid, 1999a; Ivancic, Barrett, Simonow, & Kimberly, 1997).

Movement

The type and level of movement exhibited by individuals with SMD has been the focus of study for several decades. However, the ability to make a voluntary movement has typically not been considered a quality of life indicator, rather it has been studied as the only observable indicator of learning and cognitive development in this non-verbal population.

An increase in the frequency of trained movements was presented as evidence that learning could occur in individuals with SMD. The availability of switches, devices that could be activated in a variety of ways to turn a battery operated toy or device on and off, made it feasible to automatically provide contingent responses to the individual with severe multiple disabilities (Pronger, 1995). Many single subject studies were conducted using a behavioral paradigm to demonstrate increased movements in response contingent conditions.

Although studies showing increased switch use have been criticized for not adding to quality life, it can be argued that the ability to make a voluntary movement and the cognitive awareness of the effect of that movement can only become more important to the quality of life of individuals with SMD in the future. The increasing availability of computer technology to this population already allows a person with any voluntary movement to activate an array of environmental control, communication and devices. Thus, it can be argued that the ability and willingness to make a voluntary movement will add to the individual's quality of life by offering an avenue of control and choice when typical means of communication or interaction with the environment are not possible. Finding ways to increase non- stereotypical movements that result in meaningful interactions with the environment provides the individual with more opportunity to experiment with control and feedback.

Contingent Stimulation as an Intervention

Role in Development

One intervention that has received extensive attention is the provision of contingent stimulation (also called contingent response) to children. Contingent stimulation has been defined as a stimulus that has an immediate and predictable relationship to an individual's behavior (Sullivan & Lewis, 1993). Contingent stimulation has been characterized as a reinforcer in behaviorist frameworks (Haskett & Hollar, 1978), a necessary component in the development of cause and effect in the early sensorimotor period in constructivist frameworks (Glickman, Deitz, Anson, & Stewart, 1995), and as an external control parameter in systems vocabulary.

Contingent stimulation can be social such as a mother's response to a child's vocalization or nonsocial such as a toy that squeaks when a child squeezes it. Non-social contingencies have been identified as an important part of the range of experiences of a typically developing child (Brinker & Lewis, 1982a).

It has been proposed that a contingently responsive environment has positive implication for a foundation of motivational factors as well (Lewis, Sullivan, & Brooks-Gunn, 1985). Each time that a child experiences stimulation that is contingent on his/her efforts to interact with an object, the child's expectation of control over the environment increases. Brinker and Lewis (1982b) consider that the primary developmental task facing an infant is learning how to engage and interact with the environment.

Contingent stimulation is largely missing from the lives of individuals with SMD (Langley, 1990; Lancioni et al., 1998). The nature of the combination of physical and sensory disabilities prevents these children from being able to affect their environment in a consistent and meaningful way. Investigation of ways to introduce contingent stimulation into the lives of children with SMD has been the focus of many studies. Investigations on the effect of non- social contingent stimulation on three quality of life indicators are described next.

Effect on Behavior State

No studies could be located that addressed the effect of non- social contingency responses on behavioral state organization in children with SMD. However, the availability of contingent non-social stimulation has been demonstrated to affect state organization in typically developing infants. For example, Lewis et al. (1985) examined the level of alertness that typically developing infants displayed at 10, 16, and 24 weeks of age when engaged in a simple contingency experience. Matched (age and gender) pairs of children were randomly assigned to a contingent or noncontingent sessions where they faced an apparatus which provided a visual and auditory stimulus. The stimulus consisted of the presentation of 3 seconds of a color slide of a smiling face accompanied by a children's tune.

Children who were in the contingent session could activate the stimulus with a pull of a ribbon connected to their wrist. Children who were in the noncontingent session were exposed to a similar amount of the stimulus but could not control the display. The sessions were terminated when the infant displayed poor states such as fussiness or drowsiness. The contingent participants averaged 14.4 minutes in an alert state, the non-contingent control participants averaged 8.4 minutes in alert state.

Effect on Movement

The majority of studies of learning in young children with SMD have focused on increasing specific motor responses in response to contingent "reinforcement" of that movement (Kinsley & Langone, 1995). Early on, educators realized that technology could be used to afford access to cause and effect explorations of the environment (Behrmann & Lahm, 1982; Goldenberg, 1979). An interaction that was not previously possible because of physical or sensory limitations could be provided by technology through computer switches.

The contingent responses provided by switch technology have included music (Glenn & Cunningham, 1984), visual displays and music (O'Brien, Glenn, & Cunningham, 1994), and the delivery of edibles (Gutowski, 1996). For example, Dunst, Cushing, and Vance (1985) reported an ABA single subject study with 6 participants who were profoundly retarded male infants with multiple disabilities. After six sessions of operant conditioning, 4 of the 6 participants demonstrated higher average head turns in the contingent response phase of the study as compared to the baseline (no contingent response) and return to baseline phases.

In another representative study (Realon, Favell, & Dayvault, 1988), the authors investigated whether their participants with SMD would increase the activation rate of switches during an intervention phase when the switches were connected to battery operated leisure items (such as a vibrating doll or racing car set). In both the baseline and withdrawal phases the switches were disconnected. The authors reported that 5 of their 10 participants with severe multiple disabilities, aged 18-42 years, increased rates of switch activation by 40 to 50% during the intervention phase. Switch activation rates by the participants decreased during the return to baseline.

Saunders et al. (2001) provided 8 female participants with SMD, aged 28-51, with access to switch controlled leisure items. No prompting or instruction was needed for 7 of the 8 participants to activate the switch more of the time in the feedback condition as compared to the non-feedback condition. In this study, participants were given access to the switches for up to two-hour sessions in contrast to many studies which reported 15 to 30 minute sessions.

Similar procedures were followed in other (Glenn & Cunningham, 1984; Leatherby, Gast, Wolery, & Collins, 1992) studies. Participants were first observed to discern which of their voluntary body movements might be most likely to activate a switch. The use of the switch was demonstrated for the participants. Then, a switch was presented without the contingent stimulation and number of activations counted. The switch was then connected to the contingent stimulation to determine if the participants' activations increased in this condition. A withdrawal of the contingent stimulation followed, with a resulting decrease in activations. An interesting factor is that most studies reported increased switch activations in the contingent condition by some, but not all participants. Possible reasons for the non-learners were lack of reinforcing value of the stimulation, satiation with the stimulation, lack of control of other factors such as state and inability to control the specific movement required.

In an effort to increase the availability of contingent response for young children with disabilities, the Contingency Intervention Curriculum was developed in the 1980's (Brinker & Lewis, 1982a, 1982b; Sullivan, 1990). In addition to toys operated by switches, interventionists using this curriculum also provide infants with access to personal computers. A switch activated by the child generates new visual and auditory displays on the computer monitor. Several studies replicated the result increase in rate of responding in contingent response conditions when the computer was used.

Research on using switches and toys with young children with SMD has been criticized. Kinsley and Langone (1995) write that these studies pay little attention to the generalization of switch activation skills. A second criticism was that the majority of these studies did not include any measures of self-initiated use of motor skills. There is also a lack of empirical support for the role that this intervention plays in long-term improvement in the course of cognitive development in infants exposed to the contingency intervention program as compared to those who were not (Howell, 1992; Watson, Hayes, & Vietze, 1982).

Advances in technology have required less skill on the part of the user to activate a response from the environment. One of these advances is movement sensor technology that converts any movement to a response. One of several such technologies is called Soundbeam (Jacobs, 1997). These types of technologies which provide consistent consequences for emitted behaviors so that, at an early age children may be more likely to learn about cause and effect and may ultimately demonstrate a broader array of purposeful communicative and motor response than is currently possible, (Guess, 2000). Ellis (1995, 1996, 1997) has investigated Soundbeam as a potential intervention for children with SMD. His participants are described as having profound and multiple disabilities.

An initial study (Ellis, 1995) was conducted with 2 participants who were exposed to Soundbeam for a weekly 20-30 minute session for an 11-week study. He videotaped the sessions and examined them looking for separate activities such as arm or head movement, laughter, or specific directional movement. Ellis described the progression that one of the participants made. He found an increase in the variety of movements, increase in observable positive affect, and a progression from gross to fine movements.

In a subsequent report, Ellis (1997) described the progression of one 8 year old participant over the course of two years. The child received a weekly session with Soundbeam during the school year. Ellis observed a change in the participant's movements from apparent random and agitated movements to more controlled movements which were smoother and less frequent.

Effect on Happiness Indices

An interesting consequence reported in many studies that focused on increasing movement in response to contingent stimulation was the observation that the participants displayed more positive affect in the contingent condition. Sullivan, Laverick, and Lewis (1995) reported a case study on the results of providing musical toys that could be activated by a hand switch to one participant with Rett Syndrome. In addition to the increase in switch activations that were noted they also reported that the participant's positive emotional response after six months of exposure to the contingent program also increased. They reported that the participant displayed clear anticipatory excitement when she was being positioned for switch activities.

In addition, negative emotional reactions have been reported when the contingency situation has been withdrawn as Watson et al. (1982) reported in a case study of an infant with severe multiple disabilities. The infant had demonstrated increased activation of switches connected to various stimulating toys. When the contingent situation was inadvertently discontinued. The researchers reported a change from "exuberant smiling at the fish (the stimulation) to averted gaze." p. 200

Lancioni, O'Reilly, Singh, Oliva, and Groeneweg (2002) conducted a study to compare the effect of a contingent stimulation program with a noncontingent stimulation program on happiness indices. Three participants with SMD, aged 13-46 years, were given access to switches during an intervention phase. The switches were connected to a control program that activated selected events such as flickering lights, massaging brushes, musical instruments for 8-10 seconds. These events had been previously determined to be preferred by each participant. During the stimulation phase, the reinforcing events were presented by a research assistant for one to two minutes at a time. Preceding the intervention phase, each participant was taught to use the two available switches.

The authors (Lancioni et al., 2002) found that the number of indices of happiness for 2 of the 3 participants were comparable across the intervention and stimulation phases. The participants received less stimulation in the intervention (switch activation) due to rate of activation and shorter availability of the stimulation provided by the switch as opposed to the stimulation presented by the research assistant. The authors concluded that even with less total stimulation, the contingency component was enough to provide just as much enjoyment for two of the participants as the more labor intensive non-contingent stimulation condition.

Synthesis

The unique needs of children with SMD have lead to a reconceptualization of appropriate educational interventions and assessments for this population. Children with SMD will probably not be able to obtain self-care, functional, or vocational goals. Therefore, the exclusive use of either developmental or functional curricula to frame educational interventions has proved unsatisfactory and a source of frustration for direct care providers. These children often show little change when assessments based on developmental or functional curricula are used to evaluate progress.

There is growing consensus that a quality of life framework may be a more reasonable and attainable outcome for this population. Some suggested quality of life outcomes are ability to exercise choice and some control of one's circumstances, freedom from physical discomfort, and access to enjoyable activities. Interventions focused on improving these quality of life factors may provide a better outcome for students with SMD and more satisfaction for the interventionist.

Specific assessments suggested for quality of life factors have been evaluations of the behavior state organization of the individual, evaluations of the individual's enjoyment of a provided activity, and evaluation of the amount of voluntary movement that an individual displays. Behavior state organization can be considered a foundation on which further quality of life indicators are built. If the individual is unable to regulate and maintain preferred states, the individual will be less able to benefit from environmental input and social interactions. Evaluation of the individual's enjoyment of an activity by observing the individual's behavioral indications of happiness has been suggested as one of the few ways to evaluate the effectiveness of activities designed for the individual's enjoyment. Encouragement of voluntary movement is an important quality of life factor because the ability to make a controlled movement is one method by which a SMD child can convey choice and control his or her environment.

Interventions to improve these quality of life factors may include direct one to one teaching, interactions with others through social interactions, or direct application of stimulation. Interventions can also be provided in a non-social way by arranging the environment in ways that may help the SMD individual remain alert, have an enjoyable interaction, or be encouraged to use movements.

Although many interventions are delivered effectively through one to one teaching situations, it is also important to investigate interventions that improve quality of life through independent play. Practitioners have indicated that lack of time is the largest barrier to providing quality interventions. If the children can be provided with effective uses of their own time, there is less "down time" for the child when caretakers are occupied elsewhere.

One way of arranging an independent play situation for children with SMD is to use technology. Technology provides children who have very limited voluntary movement repertoires to still interact with the environment. Dozens of switches have been developed that allow the child to activate communication devices, toys and environmental devices with very small movements. A movement sensor can be considered an improvement over a switch because any movement can activate the desired feedback. One movement sensor, Soundbeam provides musical feedback to any movement.

Obtaining these technologies, including Soundbeam, represents a significant commitment of financial resources. The current study is an empirical evaluation of the effect that Soundbeam has on three quality of life factors.

CHAPTER 3

Methods

The purpose of this investigation was to determine the effect of contingent auditory stimulation of the children's self initiated movement on three quality of life measures in young children with severe multiple disabilities (SMD). Three research questions were asked.

1. Is there a difference in the behavior state organization of a young child with severe multiple disabilities across three conditions: (a) a typical play environment; (b) the same play environment with the addition of auditory stimulation contingent to the child's movements; and (c) the same play environment with auditory stimulation provided noncontingently?

2. Within intervals where the child is observed in an alert or interactive behavior state, is there a difference in the percentage of intervals where a happiness index is displayed across the three experimental conditions?

3. Within intervals where the child is observed in an alert or interactive state, is there a difference in percentage of intervals in which the participant displays a voluntary movement?

Research Design

Single Subject Design

A multiple baseline A-BC-B-BC design (Barlow & Hersen, 1984) with 2 participants was used. During all phases of the experiment the participants were observed in independent play sessions three times a week. The baseline condition was presented for three sessions for the first participant and six sessions for the second participant. The research timeline is presented in Table 5.

Table 5

Research Timeline

		Phase	
Week	No. of sessions (cumulative)	Participant 1	Participant 2
1	3	A	A
2	6	BC	A
3	9	BC	BC
4	12	BC	BC
5	15	BC	BC
6	18	BC	BC
7	21	B	BC
8	24	B	B
9	27	BC	B
10	30	BC	BC
11	33	BC	BC
12	36	BC	BC
13	39	BC	BC

Notes.
A= Baseline
BC= Auditory stimulation contingent to movement
B= Noncontingent auditory stimulation

The investigator visited each participant three times a week to observe a play session. The first participant's play sessions were held at 3:00 pm on Monday, Tuesday, and Wednesday. The second participant's play sessions were held at 4:15 pm on the same three days. The participant was positioned in an upright position in her wheelchair for each session. In the baseline (A) phase of the experiment, the child was seated in her wheelchair with access to a typically provided play or leisure activity. In the first intervention phase (BC), the Soundbeam emitter was placed near the child and was activated by the child's movements, providing contingent auditory feedback. In the next phase (B), the Soundbeam emitter was placed in view of the child but was activated by the investigator rather than the child, providing auditory feedback that was not contingent on the child's movements. The investigator told the child that it was the investigator's turn to play with the Soundbeam. In the final (BC) phase control of the auditory feedback was returned to the child by placing the Soundbeam emitter near the child.

Variables

Independent. The independent variable was the presence or absence of auditory stimulation contingent on the participant's movements in the first intervention phase and the presence of noncontingent auditory stimulation in the second intervention phase. The nature of this intervention consisted of two components, a novel type of auditory stimulation and contingent control of the stimulation. In the BC phases the musical output was directly related to the participant's movements, that is, she was actually "playing" the keyboard through movement rather than activating an on/off switch of a musical recording.

During the B phase, the musical output was produced by the investigator rather than the participant. That is, in each B session the participant heard similar musical output than the previous phase but did not have control over it.

Dependent. Three dependent variables were measured for each play session. The first variable was the percentage of 5-second intervals that the participant was observed in a preferred state during the session. This percentage was calculated by dividing the number of observed preferred state intervals by the total number (120) of observation intervals during each session.

The second dependent variable was the percentage of preferred state intervals in which a happiness index was observed. Only intervals previously identified as preferred state intervals were coded for the presence of a happiness index. Intervals in which a happiness index was observed were called "happiness intervals." The percentage of happiness intervals for each session was calculated by dividing the number of happiness intervals by the total number of preferred state intervals for the session.

The third dependent variable was the percentage of preferred state intervals in which a voluntary movement was observed. Only intervals previously identified as preferred state intervals were coded for the presence of a voluntary movement. Intervals in which a voluntary movement was observed were called "movement intervals." The percentage of movement intervals for each session was calculated by dividing the number of movement intervals by the total number of preferred state intervals for each session.

Controlled. Controlled variables were: (a) the participant's position; (b) the amount of social interaction between the experimenter and the participant; (c) the time of day of the intervention; and (d) the type of leisure activity offered across all four experimental phases. The children were positioned in typical upright positions in their wheelchairs. One participant was always positioned directly upright, the second participant's wheelchair backrest was generally tipped back 20 degrees from directly upright as she was unable to support her head in the straight upright position.

Brief social interactions were conducted before and after the sessions, but the researcher avoided interactions during the session except as necessary to ensure the safety and comfort of the participants. All sessions were conducted after the participant's return home from school.

Ambient lighting during the sessions was dependent on outside weather as sessions for both participants were conducted in sun porch type rooms in the residence and were illuminated by light from the surrounding windows. The lighting ranged from very bright to bright. The investigator did not note any wide fluctuations in room temperatures. Background noise was controlled for the first participant by closing a door between the sun porch and the family living room. Some street noises or the voices of her siblings could occasionally be heard. Background noise for the second participant was more variable as her sessions were conducted in a room open to the dining room and kitchen although her mother did not allow any siblings to play in the same room.

Design Rationale

Single subject designs have a long history of use in investigations where the effect of interventions or treatments on individuals is of interest (Barlow & Hersen, 1984; Kazdin, 1982; Tawney & Gast, 1984; Tripodi, 1994). The researcher implements a single subject design by obtaining repeated measurements of dependent variables on one or more participants under at least two conditions; baseline and treatment. Although these designs are often associated with behavioral frameworks (Hersen, 1982; Ittenbach &

Lawhead, 1996) they are also appropriate to examine periods of development or change in systems frameworks (Oyama et al., 2001; Thelen, 2001).

Researchers using systems frameworks to study human development are challenged to closely observe individual trajectories of behavior while attempting to identify and experimentally manipulate parameters that might affect changes in the developmental course of the participant (Thelen, 2001). Single subject design, with its repeated measurements of the individuals, provides useful information on how the human system reacts to the control parameters of interest.

A basic characteristic of single subject designs, repeated measurements of the same individual, results in non-independent data. Data are usually presented in graphical form for analysis (Kratochwill & Williams, 1988; Matyas & Greenwood, 1990; Morley & Adams, 1991; Ottenbacher, 1990). However, there is growing consensus that statistical analyses can serve as a useful adjunct to visual analysis (Matyas & Greenwood, 1990; Reboussin & Morgan, 1996). The appropriateness of using various inferential various statistical procedures to analyze single subject data is a source of continuing debate among researchers (Bass, 1987; Holcombe, Wolery, & Gast, 1994; Park, Marascuilo, & Gaylord-Ross, 1990; Parsonson & Baer, 1992).

To conduct an effective single subject experiment, the researcher must design an experiment that takes into account both the characteristics of the participants and the requirements of the proposed analysis. In the current study, the investigator considered the factors of effect size, significance, statistical power, and N (the number of observations in each phase length in single subject design) in the design.

Effect Size

Cohen (1988) describes effect size as the proportion of variability in the dependent variable related to changes in the independent variable. Effect size (ES) or treatment effectiveness describes the actual magnitude of the difference between mean measures of groups rather than the p-value of a particular statistical test (Cornell & Mulrow, 1999). Komrey and Foster-Johnson (1996) suggest that effect size statistics are appropriate for use in single subject designs, as calculation of this descriptive statistic does not rely on the independence of data points. The magnitude of effect size is not affected by sample size (N).

Effect sizes related to the difference in means, can be calculated in different ways. The effect size ***d*** was used in this study. The ***d*** effect size is calculated by dividing the difference in means of two adjacent phases by the pooled standard deviation of the phases. Comparisons were made between the A and BC phase, the BC and B phase, and the B and final BC phase for each of the three dependent variables. The effect size numeral represents differences express in standard deviation units. That is, an effect size of 1.0 represents one standard deviation of difference between means (Komrey & Foster-Johnson,1996).

The use of this measure has not yet become commonplace in single subject research. Cohen's (1988) often cited conventions for psychological investigations describes a ***d*** of .20 as small, .50 as moderate, and .80 as large. Researchers who have conducted meta-analyses of treatment effects in mental health and education have found that most studies obtain effect sizes between .20 and .80 (Lipsey, 1990).

A meta- analysis that reports effect sizes of interventions with individuals with SMD has not been conducted. Therefore, there is no context in which to compare the magnitudes of effect sizes obtained in the current study. Decisions on possible changes between phases was based only on the relative size of the change for each participant relative to changes between the other phases. It has been suggested that effect sizes calculated by comparing the effect of interventions on the same individual are higher than those obtained in between- group designs where there is independence of observations (McCartney & Rosenthal, 2000). Therefore, even an effect size of .80 ("large" according to Cohen, 1988) might not represent a large change in the current study.

Significance

Significance, or the possibility that any change in mean levels of the dependent variables between phases was found by chance (Type I error), was addressed in this study by avoiding response guided experimentation decisions on phase length. Response guided experimentation as described by Edgington (1983) refers to a procedure whereby a research plots each data point as it is obtained and then makes a decision whether to change or continue the current phase of the experiment. These multiple looks at the data can be considered analogous to repeated testing (Allison, Franklin, & Heshka, 1992). There is the possibility that repeatedly examining the data in order to determine phase length increases the chance that one will stop on a high or low "bounce" leading to a greater change in level at the phase shift. Allison, Franklin, and Heshka (1992) argue that visual inspection combined with response guided experimentation could easily lead to unacceptably high Type I error rates. Therefore, phase lengths were predetermined in the current study before the experiment began.

Power Analysis and Phase Length

A power analysis involves ensuring that enough data are collected and that the level of power is set appropriately so that if an effect exists, there is a reasonable chance of detecting it, thus avoiding a Type II error (Cohen, 1988). In single subject research, the researcher must consider power when setting the phase lengths of the experiment to increase the chance that if an effect is present, it will be detected. The current study consisted of three conditions A (baseline), BC (both components of intervention), and B (one component of intervention).

Baseline (A) phase. A desirable baseline exhibits no trend and little variability. At the same time, a researcher should not unduly prolong the introduction of the intervention to the participants, especially the last participant who receives the intervention in a multiple baseline design (Kratochwill & Williams, 1988). The baseline phase should also be long enough so that any suspected temporal cyclicity of behavior is ruled out (Allison, 1992).

In the current study, the investigator decided a priori to set the baseline for the first participant at three sessions over the course of one week. The baseline for the second participant was set at six sessions over the course of two weeks. In this way, possible weekly cyclicity was evaluated, and a compromise between the often-conflicting desirabilities of a stable yet not overly long baseline was made.

First intervention (BC) phase. The investigator planned the first BC phase as a learning phase for the participants. The assumption underlying this intervention was that any treatment effect would only result if the participants gained a cognitive awareness that their actions had consequences, that is, if they learned the contingency. Contingency learning conditions have been correlated with increased movement and increased positive affect in SMD participants and increased time in alert or behavior states in infant participants.

It was necessary therefore, for the investigator to make an "educated guess" (Darius & Portier, 1999, p. 92) of the number of intervention sessions that would be needed for the participants to learn the contingency. Several studies have been conducted on contingency learning in SMD individuals and researchers have reported treatment effects after a wide range of intervention phase lengths. However, it can be argued that because consumers of single subject design research rely on logical rather statistical inference that the most appropriate reference studies would be those that most closely approximate the conditions and participants of the current study.

Published studies most similar to the current study are the case studies of the use of Soundbeam as an intervention for children with severe multiple disabilities reported by Ellis (1995, 1996, 1997). He reported increased instances of positive affect and improved movement control in his participants after 13 weekly 20-30 minute sessions (Ellis, 1997) and 11 weekly 20-minute sessions with the Soundbeam. Therefore, the investigator conservatively set the first BC phase at 15 sessions (although on a denser schedule than reported by Ellis).

Removal of the contingency (B) phase. During this phase, the investigator subtracted the contingency component of the intervention in order to examine the possibility that the novelty of the musical output was the salient factor in any difference found between baseline and the BC (both components) condition. This phase was conceptualized as a short probe of this factor. An early stopping rule was also implemented, as previous studies involving the withdrawal of any contingency from individuals with SMD have reported that removing the contingency experience can be confusing and distressful for the participants (Fields, 1999; Watson, Hayes & Vietze, 1982). If the parent or investigator noted an increase in signs of unhappiness in the participant such as crying or agitation that necessitated stopping the session, the control of the Soundbeam was returned to the participant.

Final intervention (BC) phase. The length of the final phase was slightly shorter than the first BC phase. At the conclusion of the experiment the Soundbeam was placed in the participants' classroom at school for their continued use.

Controls of Threats to Validity

The investigator followed several procedures to control threats to the internal validity of the experiment. Kazdin (1982) lists several major threats to internal validity that can be addressed either through design or procedures. The threats particularly relevant to this study included history, maturation, instrumentation, statistical regression, treatment integrity and order effects.

History and Maturation

History was a particularly significant threat because the participants attended the same classroom and followed the same school schedule. A multiple baseline design, in which the intervention is introduced at different times for the 2 participants, was used to address this threat. If changes in the dependent variable are observed in each participant only after the intervention has been implemented for that participant, then the case is strengthened for the inference that the intervention was the cause of the change.

The multiple baseline design also controls for maturation. The unequal phase lengths of the current study (the first intervention phase is longer than the other phases) may contribute to the maturation confound and some researchers (Barlow & Hersen, 1984) recommend fairly equal phase lengths in designs to control for this possibility. However, maturation was less of a threat in the current study because of the relatively short term of the experiment (13 weeks) and the slow developmental rates typical of children with SMD.

Instrumentation Error

As human observers collected the data in this experiment, there were several possible threats related to observation as a data collection method. Salient threats were observer drift, participant reactivity to observation, observer reactivity to co-rating procedures, experimenter bias, and recording equipment failure.

To counteract observer drift, two retraining-recalibration sessions (Hartmann & Wood, 1982) with the research assistant were conducted after four and after eight weeks of data collection. These sessions consisted of reviewing the original training tape of the participant, discussion, and agreement on specific indicators of states for each of the participants.

Participant reactivity was dealt with by conducting an orientation session in both the classroom and the participants' homes before the baseline sessions began. The purpose of these sessions was to ensure that the family was comfortable with the procedures and to give the participant a chance to habituate to the procedure. These sessions were videotaped and these tapes were used by the investigator and co-rater to refine the protocols for the behavior state code.

Behavior state was coded during each session so the investigator was aware of which sessions were also being rated by the research assistant. Therefore, the threats of experimenter bias and observer reactivity were relevant. Experimenter bias refers to the phenomenon of seeing what one wishes to see, which is the tendency to collect data that confirms one's hypothesis or desired outcome. Observer reactivity refers to the phenomenon of the primary observer (in this case the investigator) obtaining higher interobserver reliability scores when the person knows that a session is being co-rated. To control for these threats, two of the analyses were conducted from edited videotapes at the conclusion of the entire experiment. The investigator coded the presence of happiness indices and voluntary movement from a randomly sequenced set of videotapes of all of the sessions. Then, the research assistant rated ten of the videotapes, also randomly selected. In this way the investigator did not know which tapes would be co-rated for the measures of happiness and movement.

The coding procedure for behavior state was conducted during the experiment. Eleven of each of the participant's sessions were coded by both the investigator and the research assistant for behavior state. Interobserver reliabilities were calculated for each observational code. Reliabilities were calculated using interval to interval percent agreements. A Kappa coefficient (Salvia & Ysseldyke, 2001) which is generally considered a more stringent measure of agreement than percent agreement was also calculated. Interobserver reliabilities were reported for each participant for behavior state category, for happiness intervals and movement intervals.

To minimize the possibility of equipment failure, two cuing tapes were produced and each tape was re-timed weekly to make sure that the prompts to observe or record were exact. The investigator took two identical video cameras and extra batteries to all of the sessions.

Statistical Regression

Statistical regression refers to the fact that extreme scores tend to revert to the mean on repeated assessments. Response guided experimentation (Edgington, 1984) was not used in this study to minimize the possibility that a phase would be changed after a high or low "bounce" in the data.

Treatment Integrity

Treatment integrity refers to the fact that the treatment the participant receives should be consistently implemented. The experimenter developed and used a session log to record factors related to treatment integrity at each session (Appendix D). The surrounding environmental variables of light, background noise, and room temperature were noted.

Order Effects

The musical feedback provided by Soundbeam is different than an on-off switch to control music. The musical phrases produced are directly related to the user's movements, that is, the user is actually playing the instrument with movement. The music is original each time, it is not merely replaying a song sequence. Therefore Soundbeam music can be conceptualized as having both a contingent nature and a unique sound. Both of these components, the contingency and unique type of sound were presented in the same order for both participants. The use of the same sequence for all the participants would make it difficult to identify the salient factor (either contingency or unique sound) if differences in mean measures of the variables were found between the baseline and intervention conditions. However, the investigator considered it important to focus on contingency as the main effect and therefore presented the contingent learning condition first. This A- BC-B-BC design sequence is recommended when a researcher wishes to investigate whether some consequences do not influence behavior except under response contingent conditions (Kratochwill, 1978).

Participants

Two children with SMD participated in this study.

Selection Criteria

The participants were children who: (a) were in the age range of 2 to 7 years old; (b) received special education services under the Michigan category of severe multiple impairment; (c) were non-ambulatory; (d) were non-verbal; (e) had no identified or suspected moderate to severe hearing loss; (f) were reported to enjoy music; (g) were reported to usually enjoy independent play; and (h) had parental consent to participate in the study.

Recruitment and Informed Consent

The investigator contacted the directors of developmental centers in southern Michigan to explain the purpose of the study and seek assistance in recruiting participants. The center of the first director who indicated willingness to participate in the study was selected as the research site. A presentation about the study was made for classroom teachers who then suggested potential participants. The investigator sent a postcard with a brief explanation of the study to the family homes of potential participants. Families who returned the postcard indicating possible interest were mailed a detailed consent letter (Appendix A) and a video of the investigator demonstrating the equipment.

Parents of potential participants then met with the investigator, were given an opportunity to ask questions, review the assent procedures for their child, and saw a demonstration of the equipment. Consent signatures were obtained if the parents indicated interest in participation. The first 2 participants for whom the investigator attained parental consent were included in the study.

The parents selected the pseudonym used to identify their child participant in this report. The child's name was known only to the investigator, her dissertation chairperson, research assistant, school principal, and classroom staff. Videotapes and written material were accessible only to the investigator, parents, research assistant, and members of her dissertation committee.

Description

Two girls who receive services under the category of severe multiple disability participated in the study. They are classmates in a self-contained pre-primary classroom in a school for children with severe disabilities. Their classroom of ten students is staffed by a teacher and three teacher assistants. Table 6 provides a summary of participant characteristics. Information was obtained from school records, observations, and interviews with parents and educational staff. Short descriptions of each of the participants are provided next.

Esther. Esther is a 6 year old female who is the youngest of three siblings. She is diagnosed with genetic neurological disorder of unknown origin that resulted in developmental delay, seizure disorder, and reactive airway disease. She has received special education services since the age of 4 months. She receives nourishment via a g-button gastrostomy button. Medications are prescribed to help control seizures and muscle spasticity and to aid her breathing. Esther's teacher reports that Esther shows pleasure when being read to, can sometimes activate a single switch with assistance, and will show anticipation of her turn. She can search with her eyes for the source of sounds. She demonstrates voluntary movement of her right arm, although an ATNR reflex limits her ability to explore and manipulate objects. Esther smiles at others and vocalizes

Table 6

Characteristics of Participants

	Esther	Lucy
Age	6 years	4 years
Diagnosis	Spastic quadriplegic cerebral palsy, reactive airway disease	Rett Syndrome
Physical Abilities	Non-ambulatory, ATNR limits exploratory abilities, some voluntary movement in arms and hands	Non-ambulatory, limited functional use of hands, full range of motion in arms and legs
Sensory Abilities	Normal hearing, vision corrected for refractive error with contact lenses/glasses	Mild hearing loss, normal vision
Adaptive Behavior	Vineland Scores Communication 1 mo Daily Living Skills 3 mos Socialization 1 mo	Vineland Scores Communication 5 mo Daily Living Skills 14 mos Socialization 9 mos
Medications	Phenobarbital Baclofen Rynatan Sulfatrim Albuterol (prn)	Depakote Albuterol (prn)
Educational Services (per week)	Classroom- 30 hrs Occupational therapy- 30 min Physical therapy- 30 min Speech therapy- 30 min Music therapy- 30 min Teacher Consultant- 30 min Therapeutic swim- 30 min Nurse attendant during transportation	Classroom - 30 hrs Occupational therapy -30 mi Physical therapy- 30 min Speech therapy- 30 min Music therapy- 30 min Therapeutic swim- 30 min

Table 6, continued

	Esther	Lucy
Nutrition	Receives complete formula via gastrostomy button	Fed fork-mashed foods, developing rotary chew pattern
Adaptive Equipment	Custom molded seating system, dynamic ankle-foot orthoses, butterfly shoulder harness, Hensinger collar	Custom molded seating system, dynamic ankle-foot orthoses, butterfly shoulder harness, standing Dani wheelstand

attitudes. She currently receives the services of a teacher consultant, physical and occupational therapist, adapted physical education teacher and music therapist in addition to her classroom placement. She attends school 25 to 30 hours a week from September to June and 15 hours a week June through mid-August.

Lucy. Lucy is a 4 year old female who is the youngest of four siblings. She has received special education services since she was 11 months old and was diagnosed with Rett Syndrome at 2 years of age. Rett Syndrome is neurological disorder caused by a defective gene on the X chromosome and is characterized by slow physical growth leading to small stature for age, apraxia, display of stereotypical hand movements, and communication difficulties. Lucy's development appeared normal until about 10 months of age, when she began to display the typical symptoms of the disorder, including loss of acquired speech and hand skills. Although she has full range of motion in all extremities, she is non-ambulatory and has very limited functional use of her hands. Lucy can sit independently. Her hand stereotypies are characterized by repeated movements of both hands toward her mouth and tongue.

Lucy will smile or fuss to express her emotional state. She can make simple choices by looking at the preferred object. Her mother reports that Lucy enjoys watching educational videos and will fuss when the video ends. Lucy enjoys interacting with her siblings and has definite preferences for certain toys. She currently receives the services of a physical and occupational therapist, adapted physical education teacher, and music therapist in addition to her classroom placement. She attends school 25 to 30 hours a week from September to June and 15 hours a week from June to mid-August.

Instrumentation

Behavior State

Description. The participants' quality of behavior state organization was measured with an observational code developed by Guess and his colleagues (S. Roberts, personal communication, April 3, 2002). This observational protocol and behavior state taxonomy (Appendix B) is the latest revision in a series of codes used by Guess and colleagues. The researcher using the code is prompted by an audiotape recording to observe the participant for a 5-second interval and then is given 5 seconds to record the dominant behavior state observed.

Validity. The usefulness of the construct of behavior state organization as a predictor of future development and as a differentiating characteristic between groups of individuals has been demonstrated in research on infants and individuals with SMD. Poor behavior state organization is a predictor of poor developmental outcomes. Studies of premature infants (Davis & Thoman, 1987), infants with Down Syndrome (Prechtl, 1974), and infants with SMD (Guess, 2000) have reported state cycles that differ from typically developing infants.

Reliability. As is customary with observational codes, interobserver reliabilities of this code have been reported in previous studies using the percent agreement formula. A recent study reported overall agreement scores of 90 % (Guess, Roberts, & Rues, 2002).

Measures obtained. For each 20-minute session 120 five-second intervals of observed dominant state were observed and recorded. The results from each session yielded a number between 0 and 120 in each of eight behavior state categories with the total number being 120. The number of observed preferred state intervals was divided by the total number of intervals to yield a percentage of preferred state intervals for each session.

Happiness Indices

Description. To quantify the construct of happiness, the investigator used the Indices of Happiness observational protocol (Green & Reid, 1996). An observer using this protocol (Appendix B) is prompted by audiotape to observe the participant for a designated interval and then records whether an index of happiness was observed in the participant at any time during that interval. An index of happiness is defined as any facial expression or vocalization typically considered to be an indicator of happiness among people without disabilities. Examples include smiling, laughing, and yelling while smiling (Green & Reid, 1996).

Validity. The developers of this instrument sought to validate the relationship between observed happiness indices and actual personal happiness in two ways (Green & Reid, 1996). In the first evaluation procedure, 4 participants with SMD were assessed on preferred and least preferred stimulus using an approach and avoidance procedure. Subsequently, both the previously assessed most and least preferred stimuli were presented to the participant for equal time periods for two presentations each for three sessions. These sessions were coded by an observer who was unaware of which stimuli represented the most and least preferred stimuli. Two participants exhibited higher percentages of happiness intervals, 50% and 25% when presented with their most preferred stimuli as compared to percentages of happiness intervals of 7% and 3%, respectively, when presented with their least preferred stimuli. The second 2 participants exhibited no indices of happiness, but exhibited more frequent percentages of indices of unhappiness, 68% and 47%, when presented with their non-preferred stimuli as compared to percentages of 40% and 0% respectively, when presented with preferred stimuli.

In a second evaluation procedure, Green and Reid, (1996) asked 18 practitioners to rate videotapes of four participants on how happy the practitioners perceived the participant to be while completing an activity. The practitioners' ratings were compared to a formal count of happiness indices taken earlier by the researchers during the taping of the activity. For two of the participants, 95% of the practitioners reported that they appeared to be happier in a tape segments showing no observed indices of happiness versus tapes showing previously counted indices of unhappiness. For the third participant, 100% of the practitioners reported that he appeared happier in a tape segment containing previously counted indices of happiness versus a tape with no previously counted indices of happiness. For the last participant, 95% of the practitioners reported that he appeared to be happier in the tape showing previously counted indices of happiness versus a tape showing no observed indices of happiness.

Reliability. The developers of this code reported interobserver reliabilities of using a percentage agreement on an interval-by-interval basis. Recent studies using this code have reported an overall agreement of 98% across 5 participants (Green & Reid, 1999a) and an overall agreement of 99% across 3 participants (Green & Reid, 1999b).

Measures obtained. Only preferred state intervals observed during a session were coded for happiness indices. The number of intervals in which a happiness index was observed (called "happiness intervals") was divided by the total number of preferred state intervals during the session to yield a percentage of happiness intervals for the session.

Voluntary Movement

Description. An observational measure (Appendix B) was used to quantify the amount of movement during a session. Voluntary movement was defined differently for each participant using information provided by the participant's caregivers. Voluntary movement for Esther was defined as any movement of her right arm or hand. Voluntary movement for Lucy was defined as any movement of either leg or foot away from her wheelchair foot rest.

Validity. Quantification of movement by counting or discrete movements has been used in previous studies as a measure of understanding of cause and effect. Increases in specified movements under operant conditioning paradigms have been noted in several studies of response-contingent learning (Burch, Clegg, & Bailey, 1987; Dunst, Cushing, & Vance, 1985; Lancioni, et al., 2002).

Reliability. Interobserver reliabilities on counts of movements have been reported in previous studies (Burch, Clegg, & Bailey, 1987; Dunst, Cushing, & Vance, 1985; Lancioni, et al., 2002) ranging from 89% to 100%.

Measures obtained. Only preferred state intervals observed during a session were coded for presence of a voluntary movement. The number of intervals in which a voluntary movement was observed (called "movement intervals") was divided by the total number of preferred state intervals during the session to yield a percentage of movement intervals for the session.

Intervention

The contingent auditory stimulation provided in this experiment was generated by a movement sensor system called Soundbeam (Swingler, 1998). Soundbeam is one of several existing movement sensor technologies that provides auditory feedback to any movement of the user. The Soundbeam emitter sends out an ultrasonic beam, which is aimed at the user. The user's movements in the beam are transformed into MIDI streams that are immediately interpreted into musical sounds produced on an attached electronic keyboard. The sensitivity and range of the beam can be adjusted to the type of movements the user is capable of demonstrating. There is a direct correlation between the speed, note range, and pattern of the musical phrase to the speed, direction and range of the user's movement.

Of the currently commercially available non-tactile musical interfaces, Soundbeam has been described as the most user–friendly for the interventionist (Ellis, 1995; Jacobs, 1997). Soundbeam is marketed by TFH industries in the United States as a therapeutic device for use by individuals with SMD. Soundbeam equipment has been placed in hundreds of special schools and hospitals in over 20 countries (Swingler, 1998). An illustration of the Soundbeam components is presented in Figure 1.

Data Collection

Data Collection Schedule

The children participated in three 20-minute play sessions a week over the course of 13 weeks for a total of 39 sessions. The families selected a weekly schedule that best suited their needs for the duration of the study. Both participants' families selected a Monday, Tuesday, Wednesday schedule. Esther's sessions were held at 3:00 pm in the afternoon and Lucy's sessions were held at 4:15 pm on each of these days.

Both participants completed all 39 sessions during the 13 week time frame. During the fifth week of the experiment Esther completed the third session on a Friday due to a scheduling conflict for Wednesday's session that week.

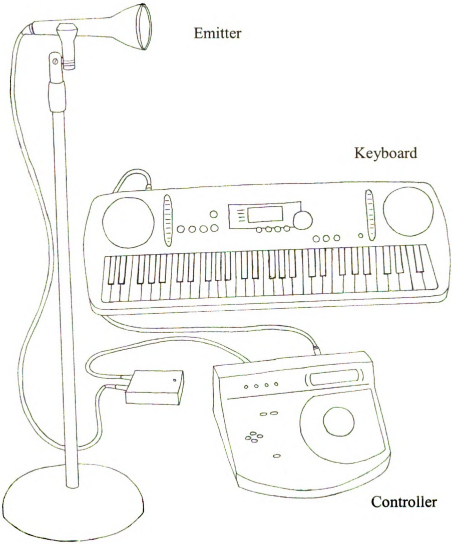

Figure 1. Components of Soundbeam Apparatus

Research Environment

All sessions were conducted in the participants' homes. The sessions were conducted in a room designated by the family. The investigator brought and set up the equipment for each session. Esther's sessions were conducted in an enclosed sun porch that was separated by a door from the family's living room. Lucy's sessions were conducted in a family room directly off the kitchen and dining room of her home. Both rooms had rows of windows on three sides and were illuminated by natural light.

Preferred activities were selected by the families for both participants to be available for the entire experiment. Esther had access to a collection of hanging toys placed by her wheelchair. Lucy was placed near a television set to watch children's videos. Esther's research environment is shown in Figure 2. Lucy's research environment is shown in Figure 3.

Data Collection Procedures

Equipment for data collection included a Sony digital Handycam video camera with tripod, a tape recorder with the cueing tape, and headphones for each observer. The headphones were connected to the same tape recorder. Observations were recorded on protocols attached to clipboards.

The experiment began in the A or baseline condition. The participant was provided with a preferred leisure activity (hanging toys for Esther, children's video for Lucy, and observed. The Soundbeam equipment was placed in the room but not activated.

In the first intervention phase (BC), the Soundbeam was activated. The Soundbeam emitter was aimed at the body part where the child exhibited some voluntary movement (Esther's right arm and Lucy's legs). Esther's typical position with the

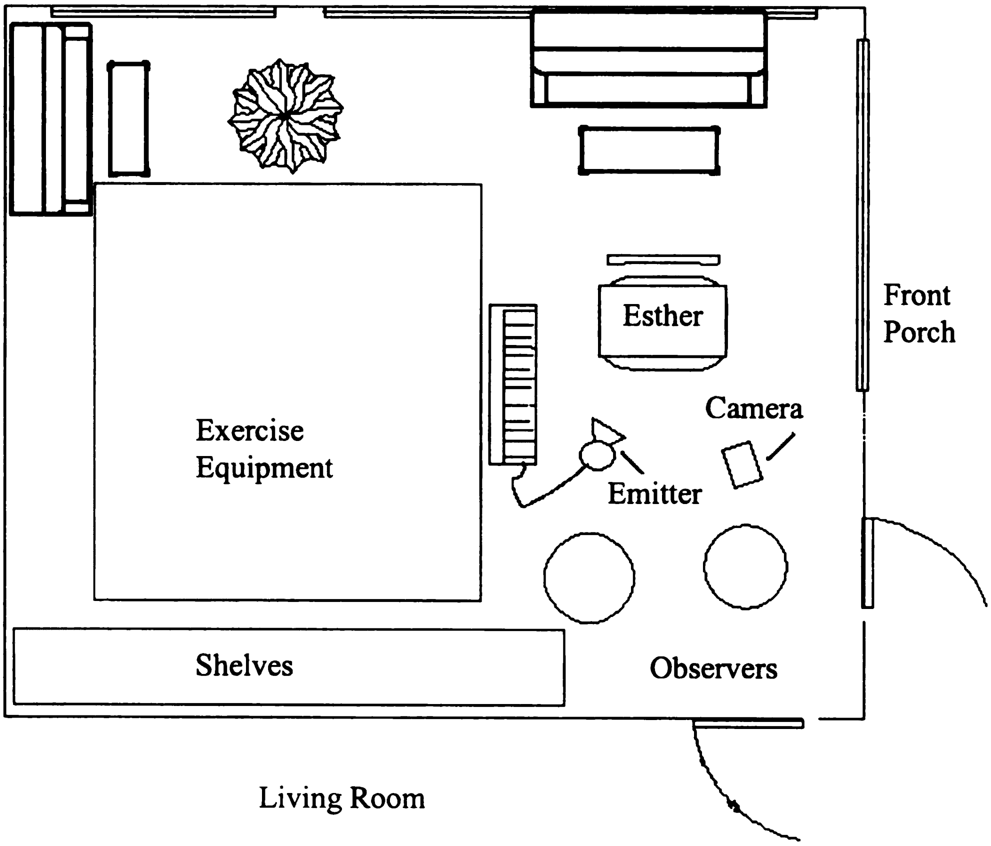

Figure 2. Research Environment for Esther

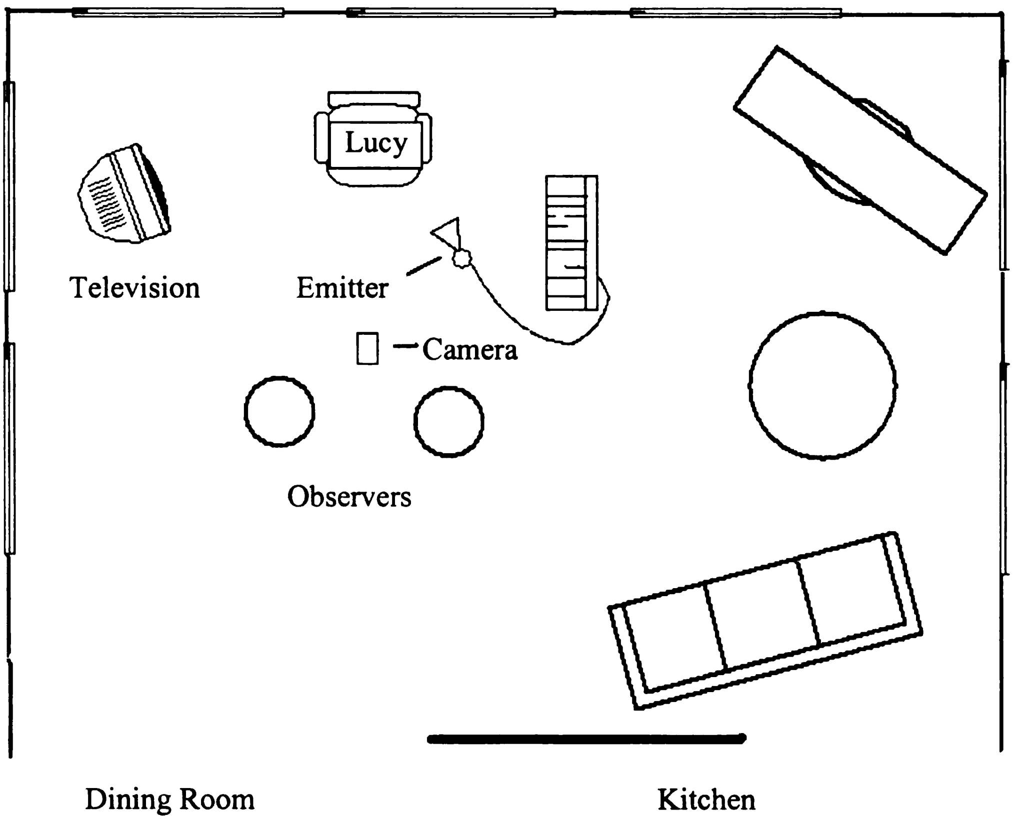

Figure 3. Research Environment for Lucy

Soundbeam emitter is depicted in Figure 4. Lucy's typical position with Soundbeam emitter is depicted in Figure 5.

During the third experimental phase (B), the control of the Soundbeam was taken over by the investigator. The participants were told and shown that the investigator would now control the music. The investigator moved her hand in the beam to generate music while the participant was both moving and not moving. An attempt was made to deliberately generate music during a similar proportion of time that the participant generally had activated the beam in the sessions in the previous BC phase. The fourth phase (BC) was a return to the conditions of the first BC phase.

The investigator coded all sessions for the behavior state variable using the behavior state protocol (Appendix B). The investigator was seated in front of each participant and wore headphones to listen to a cueing audiotape. The 20-minute audiotape cued the investigator to observe for a five second interval and then record the predominate behavior state in that interval.

Eleven sessions were also observed by the research assistant in order to assess interobserver reliability. A single jack, double headphone was used so that both the investigator and research assistant listened to the same cueing tape.

At the conclusion of each session the investigator entered field notes on the session. She recorded observations on the conditions, statements and questions asked by the parents, unusual incidents, information on antecedent events, and general impressions and questions about the session. In addition, she prepared a summary on the session which was e-mailed to her dissertation chair for discussion and reflection.

In order to complete the subsequent analysis of the second two variables of happiness and movement, the audiotape from each session was later dubbed onto the

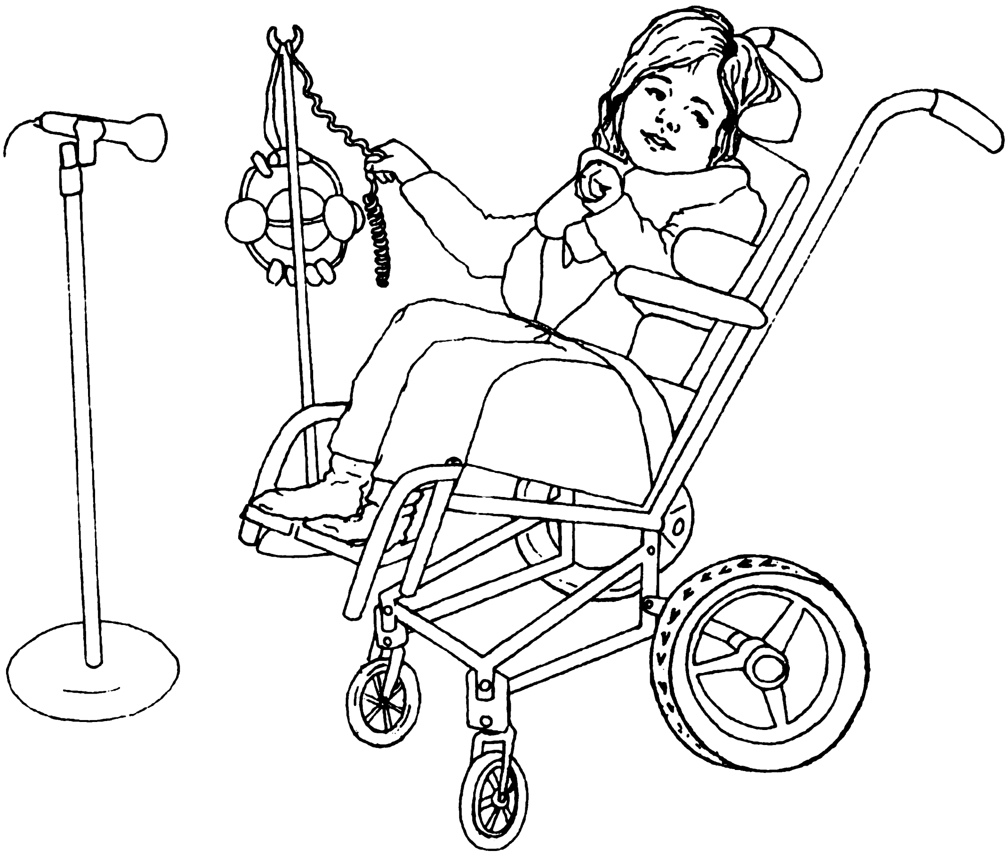

Figure 4. Typical Position of Esther with Soundbeam Emitter

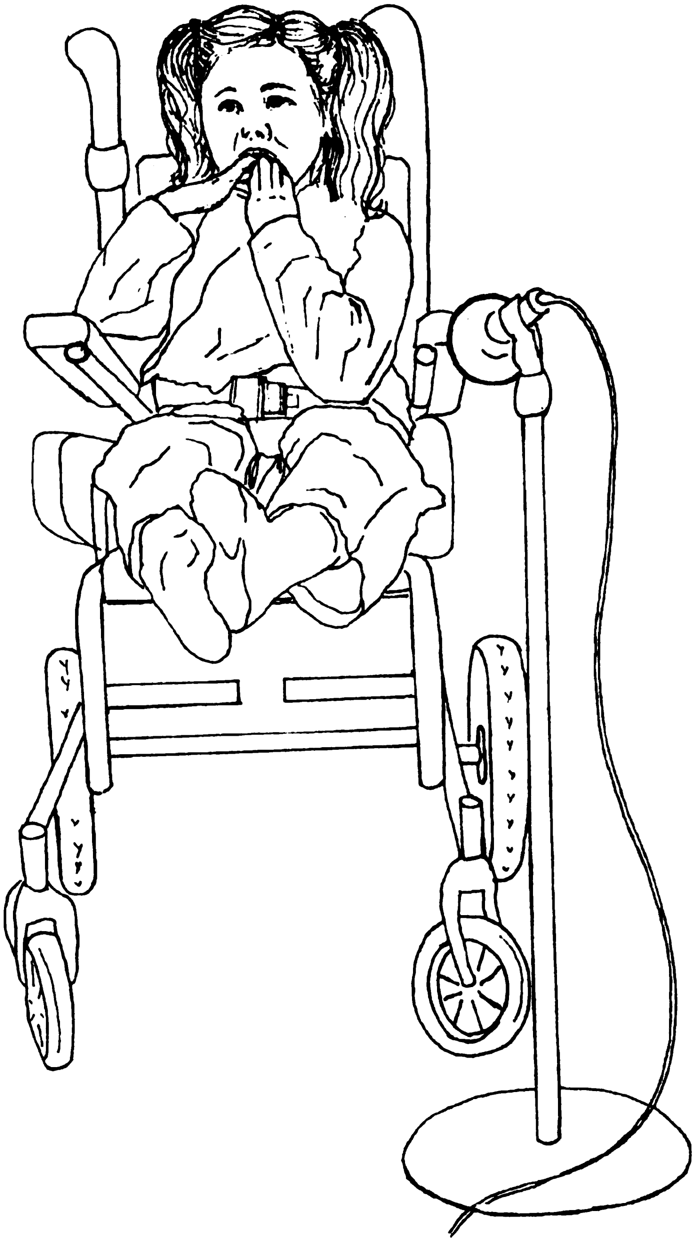

Figure 5. Typical Position of Lucy with Soundbeam Emitter

videotape using the audio dubbing feature of the camera. Therefore, a specific interval recorded on the coding sheet could be matched to the corresponding interval on the videotape. All session videotapes were then edited at the conclusion of the experiment to contain only the intervals in which the child displayed a preferred (awake/alert/inactive or interact) behavior state. These videotapes were used for the analysis of happiness indices or voluntary movements that occurred in these intervals.

Key Personnel and Qualifications

All sessions were conducted by investigator. The investigator has over 20 years of experience working with students with several types of disabilities and their families. Her experience includes 10 years in a position where she regularly made home visits as part of an early intervention program for children with disabilities. She visited the behavior state research team (Guess and colleagues) at the University of Kansas and completed training in the use of the Behavior State coding protocol at that site. She also attended an introductory session on the use of Soundbeam with individuals with disabilities conducted by the TFH (USA) Ltd. Company.

The investigator recruited a research assistant from a pool of individuals who responded to an advertisement. The researcher assistant possessed an Ed. S. degree from the College of Education at Michigan State University and had previous research experience using observational protocols. The assistant was familiar with informed consent procedures, confidentiality, and research procedures.

The investigator provided training procedures recommended by Roberts (1992) for the behavior state coding protocol. This training included: (a) viewing an introductory videotape on the construct of state; (b) memorization of the descriptions of the eight states, demonstrated by a score of 100% on a written assessment; and (c) coding to 85% agreement with the investigator on videotape samples using the 5-second interval observation protocol form on both general training videotapes and videotapes of the 2 participants in the study. A written protocol and specific characteristics exhibited by each participant was developed jointly by the investigator and the research assistant.

Training was also provided for the Indices of Happiness protocol following descriptions provided in previous studies (Green & Reid, 1996, 1999a, 1999b; Green, Gardner & Reid, 1997; Ivancic, et al., 1997). This training included reviewing the behavior state definitions and practicing the observation system along with the investigator.

Training for the amount of movement protocol included review of the definition of voluntary movement for each child and practicing the coding system along with the investigator.

Data Analyses

Data were analyzed for the three research questions in the following manner.

Research Question 1

The question on the difference of quality of behavior state organization was analyzed by comparing the percentage of intervals that the participant was observed in a preferred state (awake/inactive/alert or interact) across the phases of the study.

The data collected for this question was taken from the session coding forms, which yielded 120 observations for each session. The quality or the total percentage of intervals in preferred state was calculated by dividing proportion of intervals recorded in awake/alert and interact states by the total 120 intervals.

The percentage of preferred state intervals in each session was graphed yielding a graph with 39 measures across four phases. To evaluate the amount of change in the mean of these measures between the phases, an effect size (ES) descriptive statistic was calculated (Komrey & Foster-Johnson, 1996). The ES was calculated by obtaining the difference of the means between two adjacent conditions and then dividing by the pooled standard deviation of both conditions. Therefore, ES was calculated for the difference between Phase A and B, the difference between B and BC and the difference between BC and the final B. The effect sizes were calculated after visual examination of the graphed data for clearly visible effects or trends.

Research Question 2

For this question, preferred behavior state functioned as a control variable. All intervals in which a preferred state was observed were viewed on an edited tape of each session. Each interval in which an index of happiness was observed was counted as a happiness interval. The total number of happiness intervals was divided by the total number of preferred state intervals to yield a percentage. For example, if 100 intervals from the session were identified as being in a preferred state and 30 of them also contained at least one index of happiness, then the happiness indices measure for that session was 30%. The happiness indices measures were graphed, yielding 39 data points across the four phases.

The graph was inspected for clearly visible trends and effects. In the absence of trend, the effect size was again calculated to help describe the magnitude of change between adjacent phases.

Research Question 3

In this question, preferred behavior state again functioned as a control variable. The percentage of intervals that the participant displayed a voluntary movement in the beam was calculated and compared across phases.

The same edited tape of preferred state intervals was used to determine the percentage of intervals in which the participant displayed a voluntary movement. The data points were once again graphed and inspected for clearly visible trends and effects. In the absence of trend, the effect size statistic was calculated to describe the magnitude of change between adjacent phases.

CHAPTER 4

Results, Discussion, and Conclusions

The overall purpose of this study was to assess the effectiveness of a movement sensor called Soundbeam on the quality life of young children with SMD. Specific research questions focused on the impact of Soundbeam on preferred behavior states, indices of happiness, and the level of voluntary movement across four phases of a single-subject design. These phases were A (preferred leisure activity), BC (the leisure activity plus contingent auditory stimulation to the child's movements generated by Soundbeam), B (leisure activity with noncontingent auditory stimulation), and a return to the BC condition. Information in this chapter includes: (a) a description of the participants beginning behavior state profiles; (b) presentation and discussion of the results for each research question; and (c) conclusions based upon the results.

Behavior State Profiles of Participants

Previous research (Guess et al., 1993) has demonstrated that individuals with SMD can be described by behavior state profiles. These profiles are based upon the percentages of time that the individual spends in each of the eight behavior states of sleep, drowse, daze, awake/alert, interact, stereotypy, crying/agitated, or self-injury. In addition to information on physical and cognitive abilities, it has been suggested that behavior state profiles can be used as a further descriptor of the individuals with SMD.

The data presented in this section represent information on the behavior state profiles of the 2 participants. Specific interventions and educational programs might be more or less appropriate for individuals with different state profiles.

The behavior state protocol used in this study contains 120 five-second intervals per twenty minute session during which the observer records the predominant state observed for that interval. The total number of intervals coded for each behavior state category was summed and divided by the total number of session intervals to obtain a percentage of time in each of the eight possible categories in the baseline phase of the experiment.

A behavior state profile is generally developed by a series of observations taken at different times over several days (Guess et al., 1993). However, each participant in this study was observed at a specific time each day. Esther was observed first in the mid-afternoon and Lucy was observed next in the late afternoon. The observations on their behavior states at those times during the baseline session and comments from their caretakers about their behavior states during the rest of the day were used to determine what profile could be used to describe them as they began the experiment.

Reliability of Observations

Interobserver reliability for the behavior state code was assessed by calculating three measures of interval to interval agreement between the investigator and the research assistant, as well as an overall Kappa statistic. These measures were overall percentage of agreement, percentage of occurrence reliability, and percentage of non-occurrence agreement (Foster & Cone, 1986). The results of these calculations for each participant and behavior state category are presented in Table 7.

The first agreement coefficient, overall percentage of agreement, is calculated by summing the number of agreements on occurrence and agreements on non-occurrence of the behavior and dividing by the total number of intervals observed. This agreement coefficient is greatly dependent on chance and is most suitable when occurrence and non-occurrences of behavior are relatively equivalent as it can be inflated by the high number of agreements on non-occurrence of behavior. Therefore, in categories where

Table 7

Interobserver Agreement Percents for Individual Behavior States

	Overall Percentage Agreement	Percentage Occurrence Agreement	Percentage Non-Occurrence Agreement
Sleep			
Esther	99%	79%	99%
Lucy	NA	NA	NA
Drowse			
Esther	98%	68%	98%
Lucy	NA	NA	NA
Daze			
Esther	98%	43%	98%
Lucy	100%	75%	100%
Awake			
Esther	89%	81%	78%
Lucy	94%	80%	92%
Interact			
Esther	91%	79%	87%
Lucy	98%	36%	98%
Stereotypy			
Esther	NA	NA	NA
Lucy	94%	100%	83%

Note. A designation of NA in this table refers to a behavior state that was not observed during the intervals that were co-rated for interobserver agreement. The behavior state of self-injury was not observed in either participant.

there is a low incidence of observed behaviors, the value of this agreement coefficient will tend to be high.

During the entire experiment, Esther exhibited a low occurrence of the behavior states of sleep, drowse, and daze. Lucy exhibited a low occurrence of the behavior state of interact. High rates of agreement on the non-occurrence of those states are reflected in the relatively high overall percentage agreement coefficients.

The second agreement coefficient, percentage occurrence agreement, is calculated by dividing agreements on occurrence by agreements plus disagreements. This agreement coefficient has generally been used in previous behavior state research that used a similar coding system (Guess et al., 1990; Guess et al., 1993). The values obtained in previous research have ranged from 42% to100% (Guess et al., 1990; Guess et al., 1993).

As was the case in previous studies of behavior state by Guess and his colleagues, in the current study it was more difficult to attain acceptable reliabilities for some behavior states than others. For Esther, the lowest interobserver agreement was obtained for the daze state. This is the category that low interobserver agreement was also reported in previous studies (Guess et al., 1990; Guess et al., 1993). Examination of the protocols indicated that the states of daze, drowse, and sleep were difficult for the investigator and research assistant to agree on. The issue of differentiating between daze and drowse was addressed at both recalibration sessions held during the course of the study.

The investigator and the research assistant noted that it was sometimes difficult to closely observe Esther's eyes when her lids were lowered and her head tilted back against her wheelchair head rest, which was a common denominator in all three of these states. In addition, the first appearance of sleep intervals was not seen until a session near the end of the experiment and it proved difficult for the investigator and research assistant to agree on he exact occurrences of these states during each interval, as Esther moved back and forth from sleep to drowse in that session.

Although the percentage occurrence agreement of the two preferred states, interact and awake/alert, for Esther are higher, further examination of the protocols indicated that when there were disagreements between the investigator and research assistant involving these two states, it was generally when one observer marked interact and the other coded awake/alert. These disagreements were probably caused by timing discrepancies. As the coding protocol specifies that the coded state represents the majority of the 5-second interval, when both states were observed within one interval, the state observed for 3 seconds was coded. Esther often rapidly alternated between these two states as she touched and withdrew from her toys. A difference in one second of observation time noted by the investigator and research assistant was enough to result in a disagreement between these two states.

To summarize, further examination of the protocols for Esther indicated that disagreements between the investigator and research assistant were generally found within the aggregated category of non-preferred states (daze, drowse, and sleep) or within the aggregated category of preferred states (interact and awake/alert).

The investigator and research assistant were unable to reach acceptable reliabilities on the category of interact for Lucy. The category of interact seemed to be problematic for coding because it was a transitional state for Lucy. The participant is coded in interact state when she purposely touches or manipulates something. As Lucy didn't have many objects available for play, her physical contacts consisted of grabbing her bib or her pacifier. She invariably brought these objects to her mouth. Chewing on objects was coded as stereotypy. Therefore, most of Lucy's actions that were coded as interact were observed for just part of an interval. When this sequence happened during the five second interval, the investigator might see 3 seconds of interact versus 2 seconds of stereotypy, thus coding the interval as interact. The research assistant might see 2 seconds of interact versus 3 seconds of stereotypy, thus coding the interval as stereotypy. The reach for objects could also be preceded by a period of awake/alert state, causing a possible disagreement on whether the interval was awake/alert or interact if the timing was different of these observations by one second.

The incidence of interact state was very low for Lucy, only 33 of the total 1320 intervals observed by both the investigator and research assistant over the course of the experiment were marked by either the investigator or research assistant as this state. Of those 33 intervals, the investigator and research assistant disagreed on 21 intervals. Eleven of these disagreements were an awake/interact split and ten of the disagreements were a stereotypy/interact split. This meant that only 10 of the intervals were a disagreement about a preferred and non-preferred state.

The third agreement coefficient, percentage of non-occurrence agreement is calculated by dividing agreements on nonoccurrence by disagreements plus agreements on nonoccurrence. Therefore, the values for this agreement will tend to be higher when there are relatively fewer incidences of the behavior in that category. This was the case in the current study for the state categories of sleep, drowse, and daze for Esther and the state category of interact for Lucy.

The overall Kappa statistic corrects the formula for the first agreement coefficient, overall percent agreement by subtracting change agreement on occurrence and on nonoccurrence from both the numerator and the denominator. The Kappa values obtained for Esther were .88 for sleep, .80 for drowse, .59 for daze, .77 for awake, and .81 for interact. The Kappa values obtained for Lucy were .86 for stereotypy, .52 for interact, .87 for awake, and .86 for daze.

Overall, the percentage agreement occurrence values and Kappa statistics represent acceptable interobserver reliabilities for the purposes of this study. The lower values for some of Esther's categories represent disagreements between categories that were aggregated into non-preferred state for further analysis. The problematic reliability for Lucy's category of interact is somewhat alleviated by overall low incidence of the state for her and the fact that about half of the 21 disagreements on interact actually resulted in coding for the aggregated preferred states that were used for further analysis.

Results for Esther

Esther spent 97% of the observed intervals in either of the preferred states during the baseline phase. The total percentage of intervals that Esther was observed in the various behavior state categories during the baseline sessions is displayed in Figure 6.

Esther's overall quality of behavior state falls into Profile 1 described by Guess et al. (1993). Individuals in the Profile 1 category spend more than 75% of time in either awake/alert or interact (preferred) states with at least 20% of that time in the interact state. This impression was confirmed by her classroom teacher who reported that Esther generally appears alert during the day and rarely sleeps or appears drowsy at school unless she is ill.

It should be noted that Esther's percentage of time in the interact state during the baseline phase could be a result of the fact that toys were positioned next to her wheelchair as her preferred leisure activity. Esther was only able to reach with her right

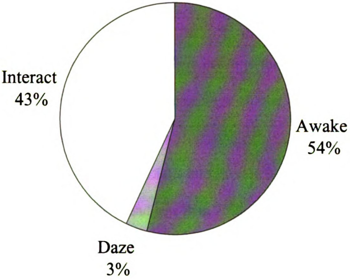

Figure 6. Percentages of State for Esther in Baseline Phase

arm and hand and had limited range of motion in that arm. Similar amounts of time in the interact state would probably not be observed during the entire day if toys and objects are not continually placed in close proximity to her right side.

Results for Lucy

Lucy spent 45% of the observed intervals in either of the preferred states during the baseline phase. Figure 7 displays the total percentage of intervals Lucy was observed in various behavior states in the baseline phase.

Lucy's overall behavior state quality falls into Profile 3 as described by Guess et al. (1993). Individuals in this profile spend less than 75% of the time in one of the preferred states and may spend much of time engaged in stereotypical behaviors. This categorization was confirmed by Lucy's teacher who reported that Lucy spends a large percentage of time in school engaged in stereotypical behaviors. However, she also reported that Lucy sleeps during the morning bus ride to school and takes a two hour nap in the afternoon. She was not observed sleeping during any of the experimental sessions conducted in the mid afternoon, suggesting that although she does need to sleep during the day, her sleep times are distinct and predictable.

The very low percentage of interact state observed during the experiment was understandable considering that the preferred leisure activity provided during each session was playing a video on the television for her. She did have access to her bib with varied textures and attached objects but her toy tray was kept at school. Her teacher reports that Lucy will interact more with objects if someone sits with her and holds her non-dominant hand while encouraging her to reach for specific objects. Restraining or weighting the non-dominant hand is a tactic that has been used successfully to increase

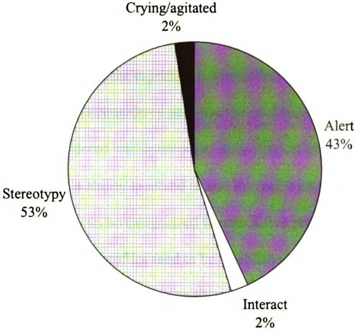

Figure 7. Percentages of State for Lucy in Baseline Phase

functional use of the dominant hand in some children with Rett Syndrome (Katsiyannis, Ellenburg, Acton, & Torrey, 2001).

Discussion

The two participants began the experiment with different behavior state profiles. Esther's behavior state profile is considered an optimum profile for learning. Lucy's behavior state profile is considered less optimum as stereotypical behavior often interferes with the individual's ability to attend to and interact with the environment.

Individuals with SMD can be categorized in one of five profiles (see Table 4), and a recent study reported that these profiles tend to be established around age three (Guess, Roberts, & Rues, 2002). Only two external conditions, position of the child and social interaction, have been correlated with preferred state in earlier studies, suggesting that the internal characteristics of an individual may exert a stronger influence over state quality than interventions that change environmental parameters, at least after infancy.

Time in Preferred States

Research Question 1 of this study investigated whether there was a difference in the percentage of time that the participants spent in a preferred behavior state across the four experimental phases of the experiment. The quantity of time in either of the preferred states is one attribute of behavior state organization. As preferred states are presumed to be the most conducive states for observation of and interaction with the environment, researchers posit that these states are where learning occurs.

The addition of Soundbeam to their play sessions had different effects on the two participants. Esther's percentage of intervals in preferred state was unaffected, while Lucy's percentage of intervals in preferred state actually decreased. The mean percentage of intervals of preferred state for both participants in the four experimental phases is presented in Figure 8. The session percentages were calculated by dividing the number of preferred state intervals by the total number of intervals of the session (usually 120). Some session percentages had to be calculated with less than 120 intervals due to recording equipment failure. Esther's Session 1 was 103 intervals and Session 28 was 99 intervals. Lucy's session 6 was 101 intervals and session 14 was 119 intervals due to a problem with the camera.

Table 8 presents the actual number of intervals in preferred state across the four phases for the 2 participants.

Reliability of Observations

Reliability data for behavior states, including the preferred states of awake/alert and interact, can be found in Table 7. The inter-observer reliability for the behavior state code protocol was reported in the previous section on percentages of all behavior states. Two of the behavior state categories, awake/alert and interact, were aggregated into one category of preferred state for analysis.

Results for Esther

The addition of Soundbeam music both contingent and noncontingent to Esther's movements did not change the percentage of intervals that Esther was observed in preferred state. The individual measures of preferred state percentages for each of Esther's sessions are presented in Figure 9. She displayed a fairly constant and high level of percentage in preferred state across all sessions. During sessions 35 and 39, Esther's displayed symptoms of a respiratory illness which worsened during the session, resulting in a higher incidence of drowse and sleep states. Descriptive statistics for each phase are presented in Table 9. The large standard deviation in the final BC phase is the result of the two sessions of illness.

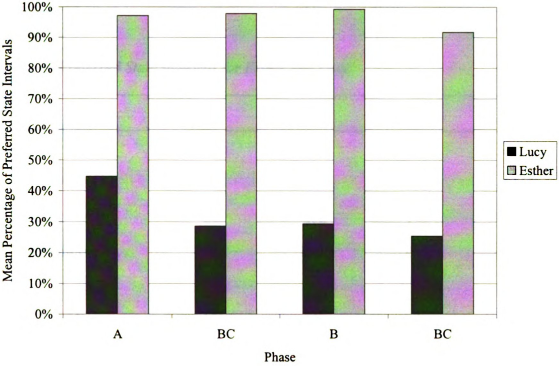

Figure 8. Mean Percentage of Preferred State Intervals for Both Participants

Table 8

Number of Preferred State Intervals for Esther and Lucy

	A	BC	B	BC
Esther				
Awake/Alert	186	1110	495	1162
Interact	147	652	199	489
Total Intervals	343	1800	699	1800
Lucy				
Awake/Alert	301	500	190	357
Interact	16	15	6	9
Total Intervals	701	1799	668	1440

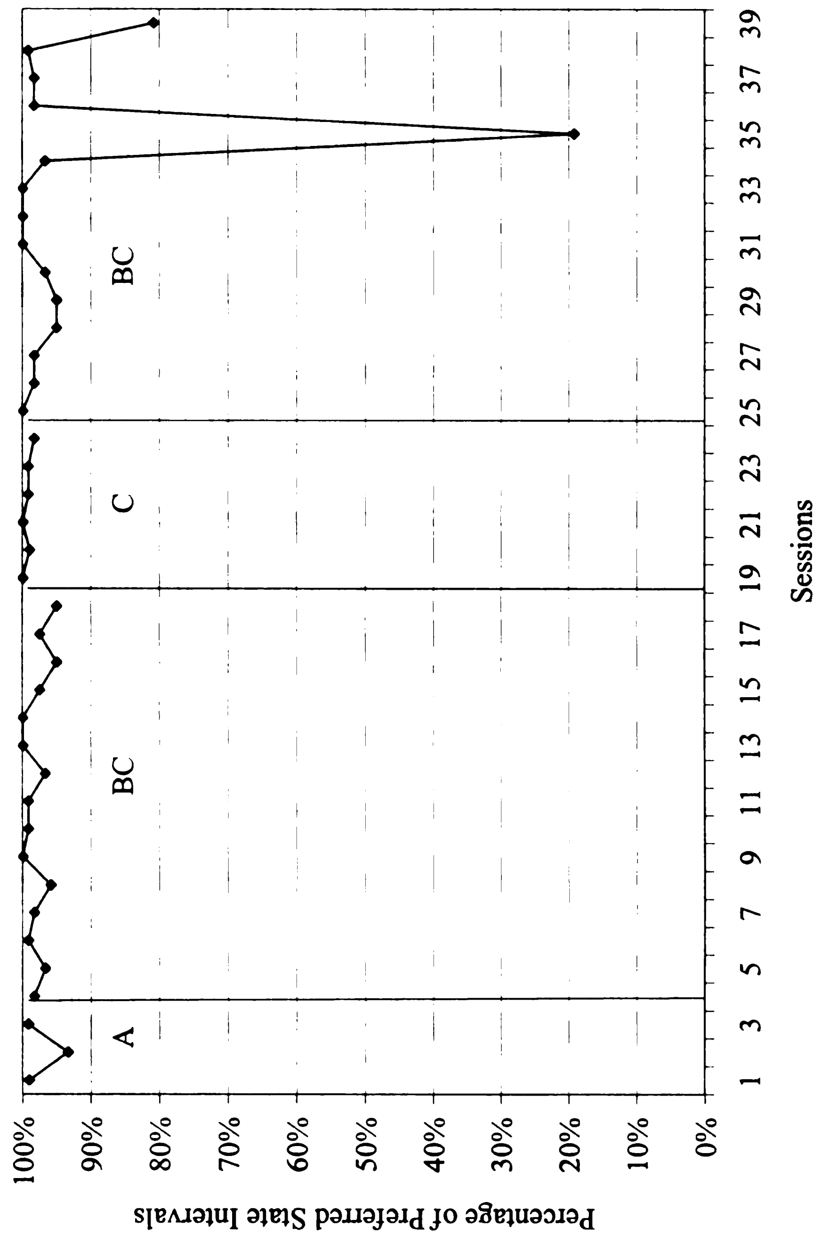

Figure 9. Percentage of Preferred State Intervals for Esther in all Sessions

Calculation of the effect size magnitudes between the phases yielded an effect size of .46 between phase A and phase BC, .56 between BC and B, and .39 between B and the final BC phase. These relatively small effect sizes confirm the visual examination of the graph. As described in Chapter 3, the effect sizes obtained in this study are used to describe relative changes in means for each participant.

Preferred states have been described as learning states in the behavior state literature, and observations of Esther seemed to confirm this idea. When she was coded in these states she was reaching for toys, holding them at different angles, moving them around using different motions, and using different finger movements to explore them. In awake/alert states when she wasn't actively exploring her toys, she often oriented to sounds around her by turning her head or visually examined her hand or the toys. Esther often paused after her movements and smiled. She also could have a look of determination on her face when she moved the toys vigorously around.

Results for Lucy

The percentage of intervals Lucy was observed in preferred state decreased after Soundbeam was introduced in the first BC phase. This relative decrease in preferred state percentage was maintained for the remainder of the experiment in both the subsequent noncontingent to movement (B) and final contingent to movement (BC) music phases. The individual measures of preferred state percentages for each of Lucy's sessions are presented in Figure 10. Descriptive statistics for each phase are presented in Table 10. Calculation of the effect size magnitudes between the phases yielded an effect size of 1.18 between phase A and phase BC, 0.0 between BC and B, and .33 between B and the final BC phase.

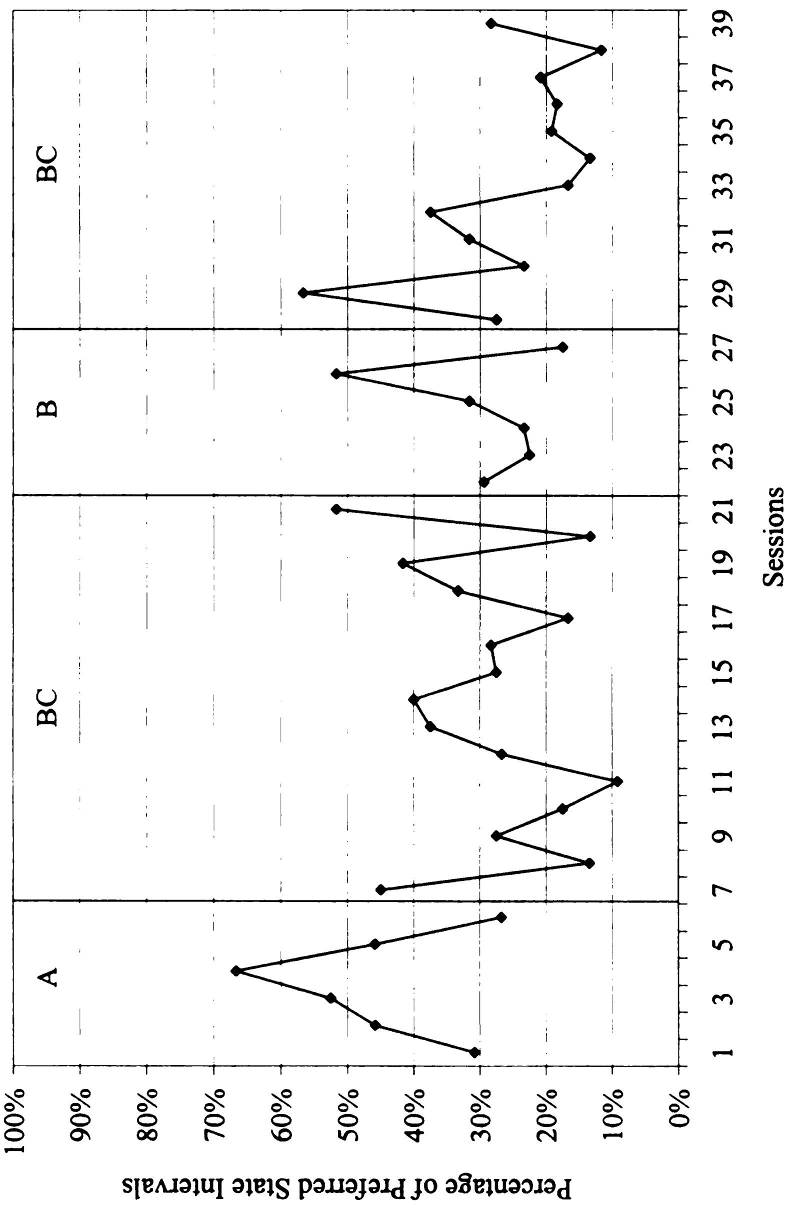

Figure 10. Percentage of Preferred State Intervals for Lucy in all Sessions

Table 10

Descriptive Statistics for Lucy – Preferred State

	A	BC	B	BC
Mean Percentage of Preferred State Intervals	45%	29%	29%	25%
Standard Deviation	14.57	13.48	12.06	12.43

When Lucy was coded in preferred state she often had a non-animated facial expression and appeared to focus intently on her surroundings. The investigator noted that longer sequences of preferred state (more than three consecutive intervals) tended to be characterized by a passive body posture. During these sequences her hands lay quietly in her lap and her body appeared almost limp as she slumped slightly back in her chair. As discussed earlier, a very small percentage of the aggregated preferred state category consisted of interact state or contact with her surroundings and these interact patterns consisted of bringing an object to her mouth to chew. Preferred state was a relatively small percentage of her total time in all phases as she displayed almost constant hand stereotypies.

Discussion

The finding that Esther exhibited little change in percentage of time in preferred state may reflect the fact that because she already displayed over 95% of the time in these states there may simply have not been much room for possible improvement. The only sessions where she displayed a lower percentage of alert state were the two sessions where she was ill. This finding seems consistent with the Guess et al. (1993) findings that profiles for individuals tend to remain stable over time.

Lucy's decrease in preferred state after the introduction of Soundbeam raises several questions of how this finding should be interpreted. Lucy began the experiment with a non-optimum profile and the introduction of Soundbeam further increased the incidence of intervals of stereotypy, a non-preferred state. Reducing hand stereotypies and increasing functional hand use is a stated goal of interventions for children with Rett Syndrome (Sullivan, Laverick & Lewis, 1995) so this intervention may be contraindicated for children with Rett Syndrome

However, Lucy's hand stereotypies may not interfere with her ability to learn from other movements she is capable of making. As hand stereotypies invariably occur with Rett Syndrome, the etiology of these stereotypes is generally regarded as related directly to the compromised nervous systems of these children (Evans & Meyer, 1999). An organic basis for this etiology contrasts with other hypothesized reasons for the expression of stereotypies in SMD individuals such as compensation for low sensory input or avoidance of particular situations (Guess & Carr, 1991; Kennedy, Meyer, & Knowles, 2000).

It may be important to shift the focus of the intervention to the encouragement of voluntary movements that can be controlled by the child rather than trying to extinguish the almost constant stereotypical movements. For example, a previous study demonstrated that a child with Rett Syndrome could learn to control her head movements (Sullivan, Laverick, & Lewis, 1995), even though her hand stereotypies did not decrease.

Children with conditions such as Rett Syndrome that invariably lead to stereotypies may be less distracted or hampered by these stereotypies as they attempt to interact with their social and non-social environments. This may indicate that in some situations, a preferred learning state for some children with particular conditions might include the presence of stereotypies. In the current study, the Soundbeam was aimed at Lucy's legs as she appeared to have more control of her leg movements.

The decrease in Lucy's preferred state may also be the result of a methodological limitation of the study. As very few toys were available for Lucy, she had little opportunity to interact with objects. Perhaps had more toys been made available, and movement of these toys provided the contingent music, the stereotypies might have decreased if she used her hands to operate the Soundbeam rather than her legs.

Happiness Indices

Research Question 2 investigated possible differences in the percentage of "happiness intervals" that were observed in the participants across the four phases of the experiment. The construct of happiness was operationalized by behavioral indications of happiness that are seen in typically developing individuals such as smiles or vocalizations.

When a smile or vocalization was observed in a preferred state interval it was coded as a "happiness interval." The mean percentage of happiness intervals for both participants in the four experimental phases is presented in Figure 11. The actual number of happiness intervals and preferred state intervals observed in the four phases is presented in Table 11.

Reliability of Observations

Interobserver reliability for this measure was assessed by calculating three measures of interval to interval agreement between the investigator and the research assistant; overall percentage of agreement, percentage of occurrence reliability, and percentage of non-occurrence agreement (Foster & Cone, 1986). The overall percentage of agreement for Esther was 100%, the percentage of occurrence reliability was 98% and the percentage of non-occurrence reliability was 99%. Calculation of all three measures for Lucy yielded a value of 100% for each.

These values indicate a high rate of agreement and are similar to those found in previous studies (Green & Reid, 1996, 1999a, 1999b) and lend confidence to the results gained from analysis of the measures.

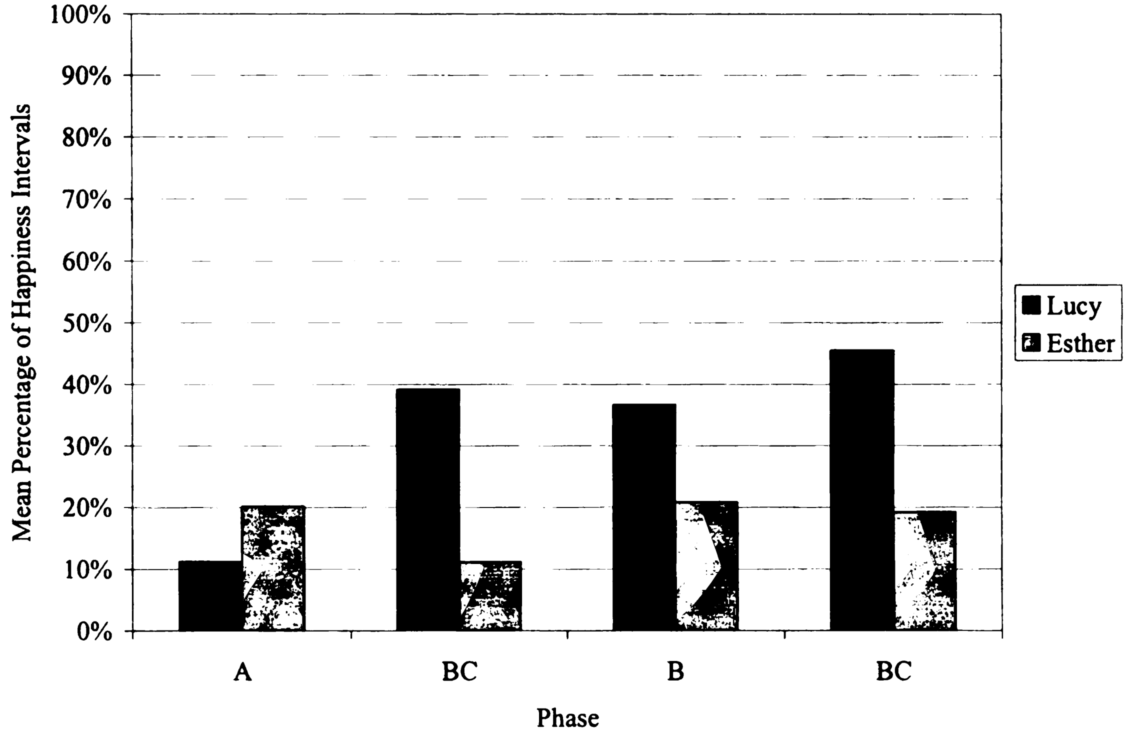

Figure 11. Mean Percentage of Happiness Intervals for Both Participants

Table 11

Number of Happiness Intervals for Esther and Lucy

	A	BC	B	BC
Esther				
Happiness	68	196	146	332
Preferred State	333	1762	694	1651
Total Intervals	343	1800	699	1800
Lucy				
Happiness	31	182	63	131
Preferred State	317	515	196	366
Total Intervals	701	1799	668	1440

Results for Esther

Esther's percentages of happiness interval were generally low across all phases and there is a slight decrease after the introduction of Soundbeam music contingent to movement. The individual measures of happiness interval percentages for each of her sessions are presented in Figure 12. Descriptive statistics for each phase are presented in Table 12. Calculation of the effect size yielded an effect size of 1.17 between phase A and BC, 1.38 between BC and B, and .14 between B and the final BC phase.

This decrease in happiness indices seems to indicate that Esther did not find the contingent music an enjoyable experience during the first phase when it was first introduced. The happiness index coded for her was a wide smile that often lingered on her face for a few seconds. The investigator noted that Esther generally did not smile while playing with her toys. Her smiles were often observed after she paused in her play or when she heard the voices of her family in the other rooms of the home.

Results for Lucy

Lucy's percentages of happiness intervals increased after the introduction of Soundbeam music contingent to music. This increase was maintained across the subsequent noncontingent and return to contingency phases of the experiment. The individual measures of happiness interval percentages for each of her sessions are presented in Figure 13. Descriptive statistics for each phase are presented in Table 13. Mean effect size calculations yielded an effect size of 1.4 between phase A and BC, .09 between BC and B, and.32 between phase B and BC.

The happiness index coded for her was a happy vocalization that accompanied a smile. Lucy's mother described her happy vocalizations as "buzzy" sounds that Lucy made only when she was excited or very happy. Lucy generally made these sounds

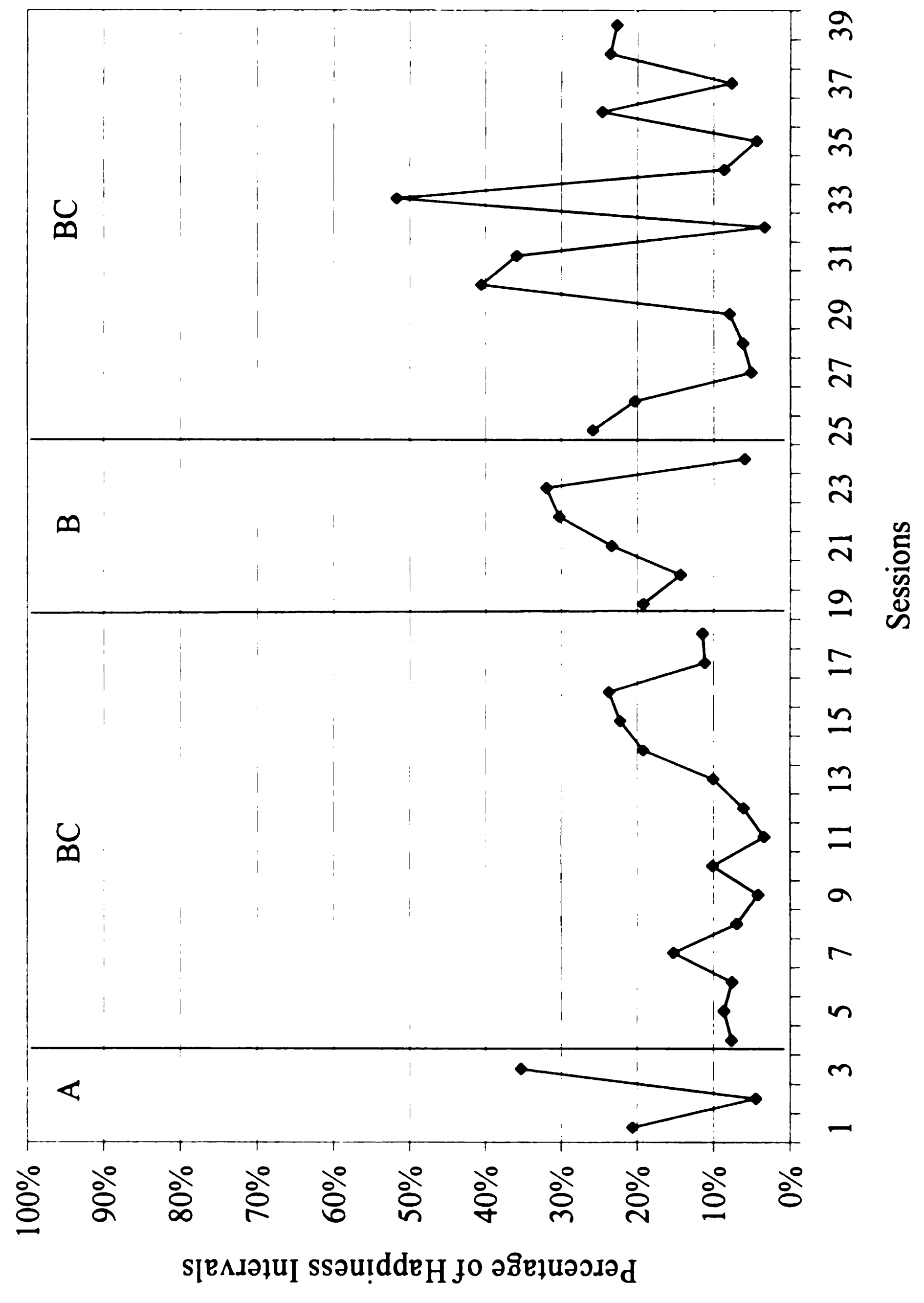

Figure 12. Percentage of Happiness Intervals for Esther in all Sessions

Table 12

Descriptive Statistics for Esther – Happiness Intervals

	A	BC	B	BC
Mean Percentage of Happiness Intervals	20%	11%	21%	19%
Standard Deviation	15.42	6.26	9.86	14.89

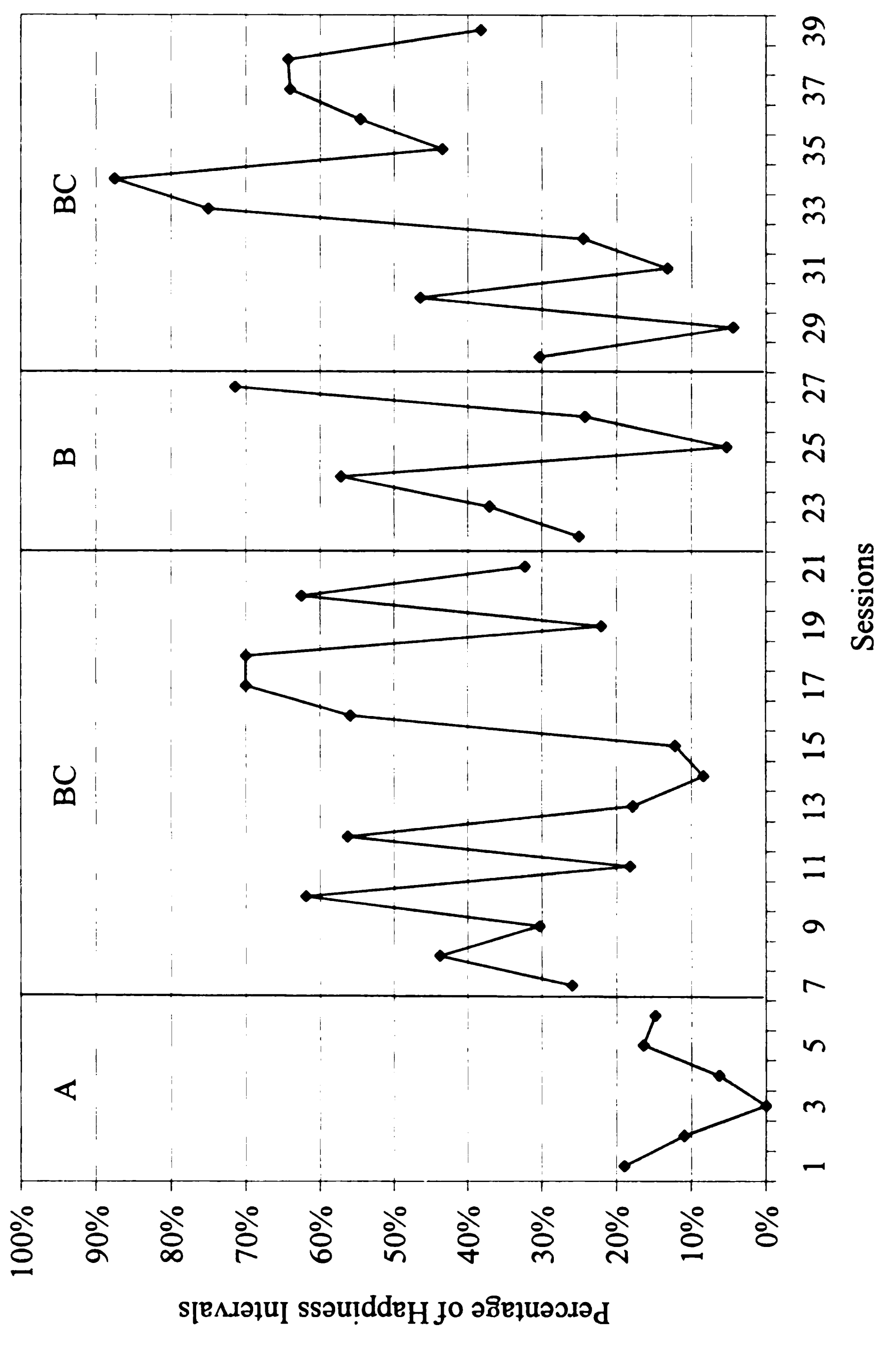

Figure 13. Percentage of Happiness Intervals for Lucy in all Sessions

Table 13

Descriptive Statistics for Lucy – Happiness Intervals

	A	BC	B	BC
Mean Percentage of Happiness Intervals	11%	39%	37%	45%
Standard Deviation	7.06	22.58	24.11	25.00

between intervals of stereotypy when she would pull her hands down, wiggle her feet and vocalize.

The percentage of happiness intervals for session 22 is based on a partial session of 69 intervals. The noncontingent condition was stopped when Lucy became upset and control of the Soundbeam was returned to her and the remaining intervals were dropped from analysis. However, she did not display any signs of non-assent for the remainder of the five B sessions so those were presented as planned.

Discussion

There could be several reasons for the finding that Esther's percentage of happiness intervals decreased with the first introduction of the contingent music provided by Soundbeam. It is possible that she found the addition of another stimulus while she was playing with her toys annoying. The distraction of the musical feedback to her movements could have meant that she received less pleasure from her play and therefore smiled less.

A second possibility could be that Esther did gain some understanding of the contingency (that her movements caused the music) but did not enjoy having to produce the music. In this case she might have enjoyed or had neutral feelings about the music as long as she didn't have to produce it. An understanding of the contingency might be the reason for the increase in happiness intervals noted after the contingency was withdrawn in the B phase. However, the decrease in happiness intervals was not replicated in the last BC phase.

The finding that Esther's percentage of happiness indices decreased may indicate that Soundbeam would not be not considered a leisure activity for her. The possible reduction of happiness intervals observed in Esther means that provision of the

Soundbeam may not be an enjoyable activity for all SMD children. Children with SMD who are not accustomed to having control of their environments may have come to prefer it that way; therefore, Soundbeam may not be considered a leisure activity but rather a work activity. In other words, the child cannot simply enjoy the music with Soundbeam, he/she has to put forth effort to make it happen. It may also be important to be cautious about interrupting a child who is concentrating on or enjoying manipulating materials by adding another sensory stimulation. It may be more pleasurable and productive for them to concentrate on one activity at a time.

The happiness protocol may be helpful to distinguish leisure and non-leisure activities from the child's perspective. Some activities such as learning to control switches or manipulate an object may require the student to focus her concentration on the activity which may not be accompanied by a smile. In this study, Esther often had a look of determined concentration on her face as she moved her toys around and activated the Soundbeam. Even with her lack of apparent enjoyment of the activity, learning the contingency may ultimately be a valuable use of her time if she gains experience and comfort with control.

The decrease noted could also be a result of a methodological limitation in the experimental design. The very short and unstable baseline limits interpretation of the change because of the wide variance of the three measures.

In contrast, Lucy did appear to enjoy the addition of Soundbeam music to her leisure activity. The investigator had also noted that Lucy seemed happier in the BC phase. Lucy's mother told the investigator after several sessions of the Soundbeam, that Lucy just "brightened up" when Soundbeam was being set up for her.

Because her percentage of happiness indices did not decrease on average when the contingency was removed in the B phase, there is no evidence that she learned or did not learn the contingency component. She did have one adverse reaction to the removal of the contingency in the first B session when the Soundbeam emitter was not placed near her. After about eight minutes of the investigator producing the music, Lucy began to make loud, whining vocalizations and her eyes filled with tears. Her mother said that Lucy was very upset.

In accordance with the assent procedure of the study, the investigator returned control of the Soundbeam to Lucy by placing the emitter near her. Lucy was content for the remainder of the session, and did not become upset during the subsequent sessions without Soundbeam control. The mean for percentage of happiness intervals did not decrease in the B (noncontingent phase), so there is no evidence that the contingency component was necessary for her to enjoy the music.

Voluntary Movement

The final research question investigated possible differences in amounts of voluntary movements across the four experimental phases. The Soundbeam emitter was aimed to insure that movements the participants were capable of controlling would result in musical feedback. The emitter beam was aimed at Esther's right arm and hand so that her movements with her toys activated the instrument. The emitter beam was aimed at the lower half of Lucy's body so that her leg movements activated the instrument.

The participants had different reactions to the introduction of the contingent and noncontingent music. The mean percentage of movement intervals for both participants in the four experimental phases is presented in Figure 14. The actual number of

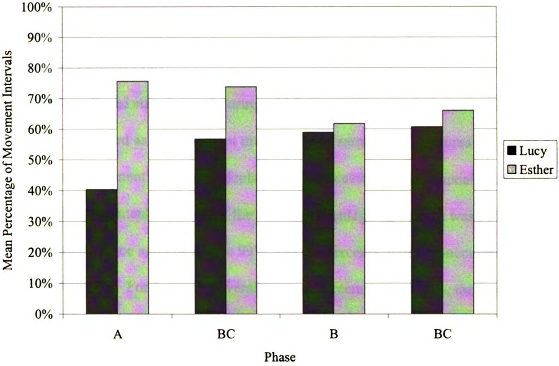

Figure 14. Mean Percentage of Movement Intervals for Both Participants

movement intervals and preferred state intervals observed in the four phases is presented in Table 14.

Reliability of Observations

Any preferred state interval during which the participant displayed a voluntary movement was coded as a "movement interval." The same three measures of interobserver agreement that were calculated for the previous observational codes were calculated for movement. For Esther, the overall percentage agreement was 99%, the percentage occurrence agreement was 99%, and the percentage of non-occurrence reliability was 97%. For Lucy, the overall percent agreement was 99%, the percentage occurrence agreement was 95% and the percent non-occurrence reliability was 98%. These values indicate a high rate of agreement and lend confidence to the results gained from analysis of the measures.

Results for Esther

Esther maintained a similar average of movement intervals across all phases of the experiment. The introduction of both contingent and noncontingent music of Soundbeam did not affect her percentages of movement. The individual measures of movement interval percentages for each of Esther's sessions are presented in Figure 15. Descriptive statistics for the means of the phases are presented in Table 15. Calculation of the mean effect sizes yielded an effect size of .15 between phase A and BC, .81 between BC and B, and .28 between B and the final BC phase.

Although Esther, who has cerebral palsy, seemed to require a lot of energy to move her arm, she did display a variety of purposeful movements across all phases. She was observed to shake, bat, grasp the toys, as well as explore them with her fingers.

Table 14

Number of Movement Intervals for Esther and Lucy

	A	BC	B	BC
Esther				
Movement	252	1300	433	1115
Preferred State	333	1762	694	1651
Total Intervals	343	1800	699	1800
Lucy				
Movement	120	286	112	190
Preferred State	317	515	196	366
Total Intervals	701	1799	668	1440

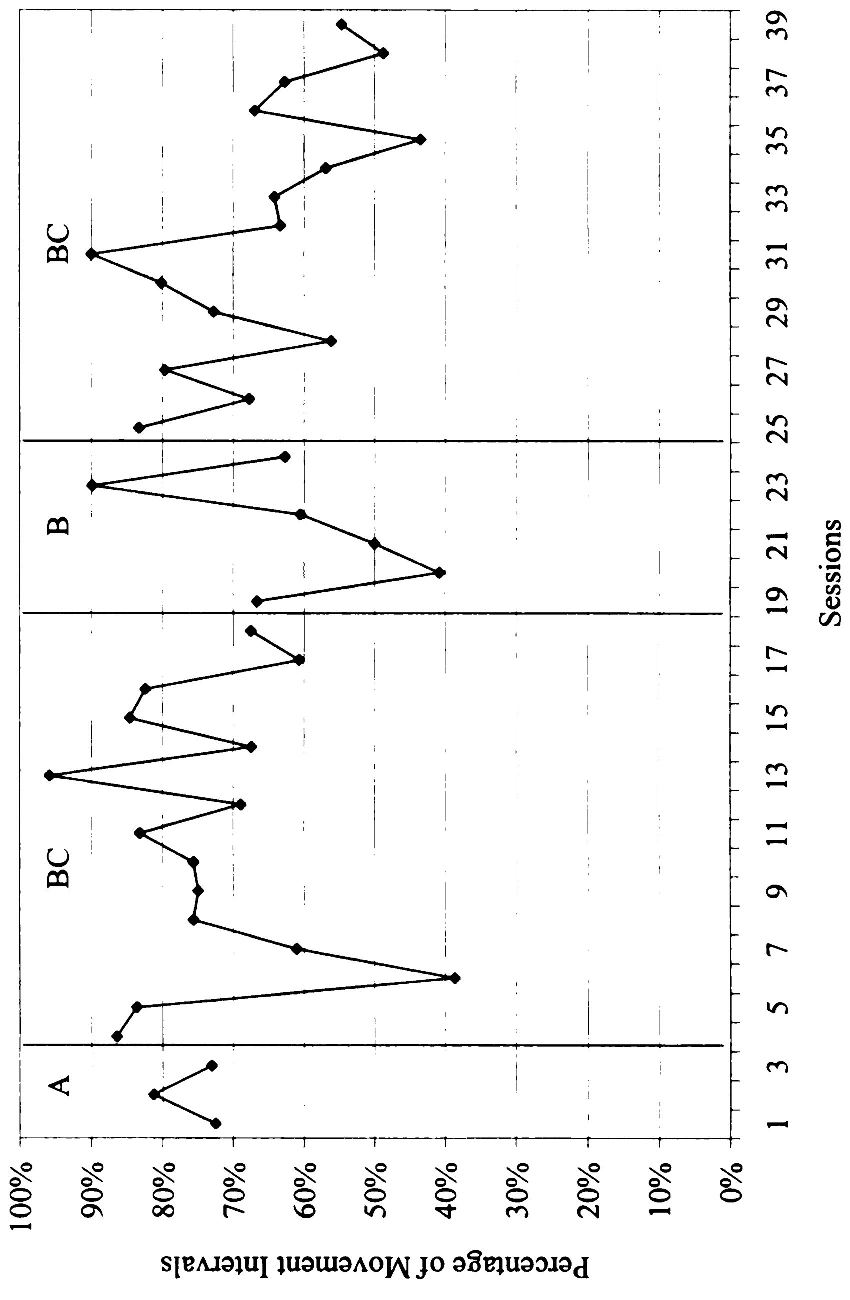

Figure 15. Percentage of Movement Intervals for Esther in all Sessions

Table 15

Descriptive Statistics for Esther – Movement

	A	BC	B	BC
Mean Percentage of Movement Intervals	76%	74%	62%	66%
Standard Deviation	4.87	13.89	16.71	13.32

Although the Soundbeam did not appear to increase Esther's amount of movement after it was introduced, her movements that activated Soundbeam in the contingent phases brought an enthusiastic reaction from her mother. Her mother was not in the same room with Esther and the investigator but could hear the Soundbeam through the living room door as she went about her household tasks. When Esther was returned to the living room her mother often commented on the session. She made comments such as "I heard that pretty music you made, it was even better than yesterday" or "Wow, you were really going to town in there." Esther smiled at the enthusiasm in her mother's voice.

Several researchers have written that one of the most important effects of technologies such as Soundbeam that allow children to cause an effect may be the opportunity for the child's caretaker to see the child as a competent individual who can make something happen all by herself (Dunst, et al.,1985; Sullivan & Lewis, 1993). Esther's mother assumed that Esther knew she was making the music, whether or not this was truly the case. The music production gave her mother a chance to comment on her daughter's performance and praise her "good job." The long term effects of seeing the child as one who understands the contingency may help make it a self fulfilling prophecy.

Results for Lucy

Lucy exhibited an increase in movement interval percentages after the introduction of the Soundbeam. This increase was maintained even after the withdrawal of the contingent component. The individual measures of movement interval percentages for each of Lucy's sessions are presented in Figure 16. Descriptive statistics for the means of the phases are presented in Table 16. Calculations of the mean effect sizes

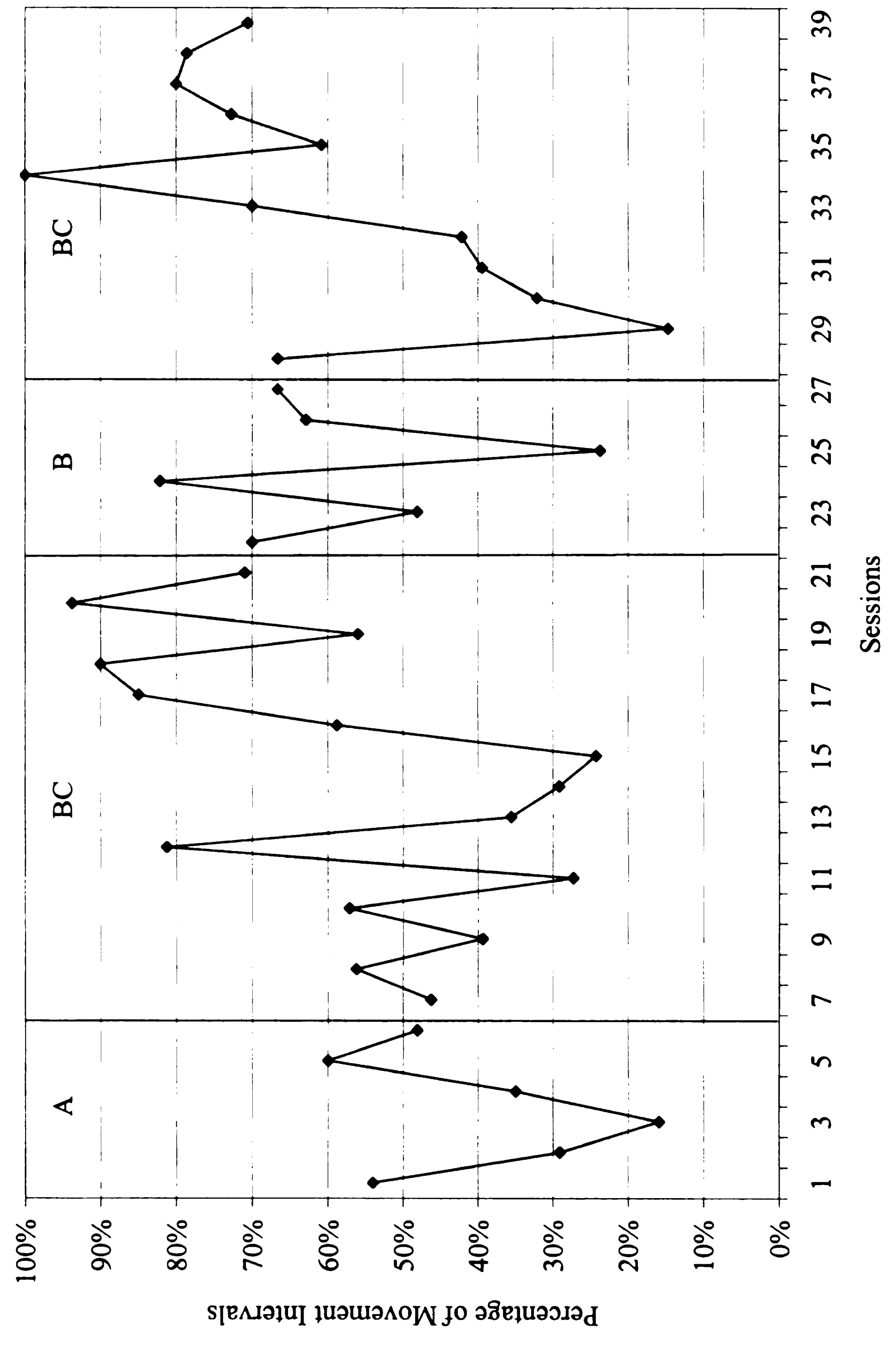

Figure 16. Percentage of Movement Intervals for Lucy in all Sessions

Table 16

Descriptive Statistics for Lucy– Movement

	A	BC	B	BC
Mean Percentage of Movement Intervals	40%	57%	59%	61%
Standard Deviation	16.67	24.67	20.47	23.98

yielded an effect size of .73 between phases A and BC, .08 between BC and B, and .09 between B and BC.

Lucy's movements were characterized by a variety of leg movements both in tandem and single away from the footrest of her wheelchair. She was observed lifting one leg above waist level and often extended both legs with a flutter kick of her feet. Leg movements were observed during both preferred intervals and those intervals characterized by hand stereotypies. Lucy was able to generate several different types of musical sequences because she was able to move her feet in different areas of the beam and through a wide range of motion.

Lucy's mother also commented on Lucy's movements, often during the session itself which she could observe from the kitchen or dining room. Her mother noted specific movements by saying "What a pretty sound you made, I liked that a lot." Her mother also noted that Lucy only made certain movements during the experimental sessions. As the investigator was setting up the Soundbeam for one session, Lucy lifted one foot above her head in a graceful up and down sweeping motion. Her mother said, "See, she never makes that movement unless you (investigator) are here."

Discussion

Examination of Esther's graph of percentage of movement intervals revealed both that her average amount of movement intervals remained unchanged during the entire experiment and that there was extreme variability in these percentages from session to session. This variability suggests that there were other factors more strongly associated with Esther's ability and/ or willingness to move her arm than the presence or absence of both the contingent and noncontingent music provided by Soundbeam.

One factor that appeared to be strongly associated with percentage of movement was Esther's health. It was the investigator's impression that the amount of movement that Esther was able to make on any given day depended on her breathing abilities. She was often observed to stop and rest between movement sequences to catch her breath. When her breathing ability seemed particularly compromised on a given day by extra congestion, each time she moved her arm, she would begin to cough. After each coughing spell she seemed to need to rest and recover.

Although her physical ability to sustain her movements varied, the fact that there was no change in mean levels of movement interval percentages across all phases of the experiment may indicate that, similar to the behavior state organization, Esther had already reached the ceiling level for this measure before the experiment began. That is, Esther participated in her leisure activity, playing with the toys, already as much as she was physically able to do on any given day. Her motivation to interact with her environment was already in place and it was not changed by the addition of either contingent or noncontingent musical feedback to her movements.

Lucy did show some change in the percentage of movement intervals as they increased after the first introduction of the Soundbeam. The change came at the same point in the experiment that changes in the other two variables occurred, after the introduction of the intervention in the first BC phase with no change after that in the subsequent B phase.

The finding that all three measures changed only after the first introduction of contingent music seems to reflect Lucy's understanding that the Soundbeam provided a different experience than the auditory soundtrack of her videos and that she enjoyed the experience. However, the fact that removal of the contingency component in the subsequent B phase seems to indicate that Lucy either did not learn the contingency, or did learn it and accepted the fact that it was removed as there was no reduction in her leg movements that had originally activated it in the first BC phase.

Conclusions

The three research questions asked in this study looked at the effect of a specific movement sensor, Soundbeam, on quality of life factors in two young girls with SMD. The questions all concerned whether there a difference in the level of measures taken of these quality of life factors between any of the experimental phases of the experiment. The answer to these questions seems to be a qualified yes, a difference was detected on one measure for one participant and all three measures for the second participant. However the differences detected were small and only occurred at the first introduction of the intervention for both participants.

One conclusion from the results was that Soundbeam and similar interventions that provide contingent stimulation to the individual's actions do not affect children with SMD in a "one size fits all" way. The effects of the intervention may be dependent on the behavior state profile, a factor that has not generally been used when describing participants in a study.

The effect of Soundbeam seemed to be almost insignificant for the first participant, Esther. The only difference on the three measures was that she seemed less happy when given contingent control of the music in the first phase. Soundbeam should probably not be considered a leisure activity for this participant. The use of Soundbeam did not affect the other two quality of life measures, probably because this participant already maintained an optimum state profile and already used her movement abilities as much as she could.

The second participant, Lucy, did appear to show some effects but it was unclear which component of the intervention, the contingency or the music itself caused the changes in her measures. In Lucy's case, Soundbeam could be used as a leisure activity with the caveat that this instrument increased the percentage of time she spent in the non-preferred state of stereotypy. Using Soundbeam to decrease the incidence of stereotypies was not successful in this study.

A second conclusion is that the use of multiple measures of quality of life provided more insights about possible interpretations of the participants' reactions to the intervention than measures based on developmental or functional frameworks. Although only small differences were found and differences were not found for all factors, the measures proved sensitive enough to detect some differences over a relatively short period of time. One participant showed a change in affect after the introduction of the intervention. The change in all three measures for the second participant, strengthened the conclusion that she realized that there was something different about the contingent and noncontingent music conditions as compared to her preferred leisure activity alone.

A third conclusion is that even though Soundbeam may not directly affect all of the child's quality of life factors in the short term, the effect of this intervention on others close to the child may ultimately prove beneficial. Children are part of a family and social system. They may be affected by other's perceptions of their competencies and understanding of the environment. The observation that the parents of both participants in this study assumed their child had attained a new competency and praised them for it may have long term effects on the parent's expectations of the child. A series of these interactions may be the base for an expectation of competency that would expose the child to more situations in which she is expected to exercise control and choice, a foundational idea of quality of life.

A fourth conclusion is that this study did not provide conclusive evidence that Soundbeam is more effective than other alternatives in improving the quality of life factors measured for young children with SMD. However, Soundbeam proved to be a sturdy and user-friendly piece of equipment. It took less than one hour for the investigator to learn to assemble the components and change the settings of the control unit. The Soundbeam equipment was set up and taken down over 70 times during the experiment, with no equipment failures. The components could be configured in different ways to fit the space available for the children's play sessions. The concept of moving through a beam to change output from the instrument was easily understood and readily observed by family members who watched the child interact with the instrument. However, as obtaining a Soundbeam represents a considerable commitment of financial resources, practitioners may want to explore alternative methods of providing contingency experiences for children with SMD.

Chapter 5

Implications, Limitations, Recommendations, and Summary

The availability of contingent stimulation provided by Soundbeam would be described in a systems framework as an external or exogenous parameter manipulated by the interventionist. As contingent stimulation is generally missing in the lives of children with SMD its role as a possible control parameter in maintaining preferred states, as well as the children's reactions was investigated.

The three quality of life measures used in this study are instruments that proved to be sensitive enough to detect changes in the participants' responses to this contingency response intervention over relatively short time period. The use of developmental scales such as the Bayley developmental scales or adaptive behavior instruments such as the Vineland used in some earlier studies of contingent stimulation interventions with individuals with SMD did not detect changes in the participants' behavioral repertoires even after the interventions had been provided for several months (Howell, 1992; Landesman-Dwyer & Sackett, 1979). The use of assessment within a quality of life framework demonstrated that some aspects of the behaviors of children with SMD can change rather quickly. The use of the quality of life assessments can help determine if the interventions should be continued or should be withdrawn. For example, in this study, the fact that Esther did not seem to enjoy the contingent music when it was first introduced indicates that it should not be considered a leisure activity for her.

As was the case in this study, individuals with SMD have often been found to exhibit highly variable responses to the same activity from day to day and also have been found to respond differently to the same intervention (Lancioni et al., 2002; O'Brien, et al., 1994; Realon, et al., 1988). However, several implications can be drawn from the effect of this intervention on each of the three factors of quality life that were measured.

Implications

Behavior State

The finding that the participants'overall quality of behavior state did not change after the introduction of contingency response reinforces earlier findings that the quality of state profiles of individuals with SMD is very difficult to change with environmental intervention alone and seem to stabilize around age three (Guess, Roberts, & Rues, 2002). The possible effectiveness of contingency response interventions to improve profiles might be maximally effective when implemented with younger children and infants. This finding underscores the possible importance of providing contingent environments to infants with SMD (Guess, 2000).

Teachers may want to plan extra activities for children who, similar to Esther in this study, already exhibit optimum profiles. These children may not need the rest periods or "down time" that are often part of classroom daily schedules (Roberts, 1992). During the down times which occur due to other staff responsibilities, providing interactive and contingent response activities can help optimize the child's time.

Happiness Indices

The fact that one participant (Esther) did not find the first introduction of contingency response to be enjoyable confirms earlier findings that caretakers and others may not know what activities may be preferred by an individual with SMD (Bannerman, 1990; Everson & Reid, 1997; Favell, et al., 1996). The investigator assumed that the provision of contingency response with music would be an enjoyable experience for Esther but it did not increase her incidence of happiness intervals. Teachers and caregivers may want to conduct a preference assessment (Leatherby, et al.,1992) before providing leisure activities.

The fact that the Happiness Indices assessment was sensitive enough to detect changes in affect in the 2 participants even after a short intervention period may make it useful for teachers who wish to plan both leisure and work activities for their students. Teachers may use the observational protocol to insure that leisure activities they have chosen for their students are, in fact, activities that are enjoyed or preferred by the student.

Voluntary Movement

The investigator's observation that the parents of both participants often commented on their child's movements implies that teachers and caretakers should seriously consider setting up play areas in which the child's movements cause "something to happen." If children are give access to contingent environments, it increases the chance that their movements, whether intentional or not, will activate a stimulus that invites a response from others. The resulting increased social interactions may be just as valuable as the opportunities to experiment with cause and effect.

Although Soundbeam technology may not be commonly available, there are many alternatives to providing opportunities for contingent responses. Different arrangements of toys, switches, and hanging objects can be positioned near the child (Dunnet, 1999; Kinsley & Langone, 1995; Lancioni, et al., 1998; Saunders, et al. 2001). For example, in the current study, Lucy's mother was impressed with her daughter's varied foot movements in the Soundbeam and decided to attach bells to Lucy' shoes so that she could continue to receive auditory feedback to her leg movements.

Limitations

The conclusions and implications drawn from this exploratory study must be regarded with caution due to several limitations. Limitations in both the research design and the instruments used are discussed next.

Research Design

The generalizability of single subject designs depends on logical inferences made from repeated replications of the effect of the intervention across participants. Unfortunately, no general inference can be made from this study as different results were obtained for the 2 participants. In addition, the use of only 2 participants greatly decreased the chance of determining a representative reaction to the intervention.

When large variances of measures within a phase are obtained, as was the case in this study, there is concern about experimental control. There were several variables in this study that could have been better controlled by the investigator.

One notable source of variability was the health of the participants. Children with SMD can have widely fluctuating levels of health from one day to the next (Ault, et al., 1994). The investigator could have implemented more stringent criteria of the participant's daily health in order for the participant to complete a session. For example, the nurse in the participants' classroom could have been asked to assess the child's health on a predetermined scale which included such factors as body temperature, observations on indications of sickness. A low rating for the day could have been cause for rescheduling the session.

Another source of variability was the different antecedent events before the experimental sessions. Two sessions during the first BC phase were held on days when school had been cancelled because of inclement weather. Week five of the first BC phase coincided with the children's spring vacation from school. This type of variability could have been controlled by scheduling the study during a period that didn't include a school vacation.

A third source of variability may have been changes in the preferred activity that were offered across all the phases. Esther was given different toys to play with and different videos were played for Lucy in order to avoid satiation with the same activity. However, the rotation of these toys was not controlled so that the same rotation was offered in each phase. The investigator could have offered the preferred activity for equal amounts of time in each phase in order to insure that the possible differing levels of attractiveness of these activities did not affect the participants' reactions.

In addition to the existence of several possible confounding variables, other limitations of the research design could have lead to incorrect findings. An alternative explanation of the finding that Esther's happiness indices decreased after the A phase may simply be the result of the short and unstable baseline. A longer baseline might have produced a mean more similar to the final three phases as the third data point (possibly an outlier) would have had less effect on the mean of a phase containing more than three data points.

A second alternative explanation for Esther's decrease in happiness may be that she simply did not like the type of music produced. Although the music output was selected by Esther's music therapist as appropriate for her developmental level, a preference assessment could have been conducted to insure that each participant enjoyed this type of stimulus.

The finding that Lucy did not understand the contingency component of the intervention (as her movements and smiles did not decrease when it was withdrawn) may also have resulted from a limitation of the design. After her initial protest when the investigator removed the emitter, Lucy may have simply accepted that it was the investigator's turn to make music. The music was still contingent on the investigator's movements and as such, Lucy may have understood that it was still enjoyable for her to observe and listen to.

Instrumentation

The results of this study should also be interepreted with caution because of possible concerns about the construct validity of the assessment instruments used. Quantification of quality of life is an emerging area of assessment and the use of these assessments in studies such as this one may raise questions about how the constructs they are designed to measure are operationalized.

A basic assumption of the first quality of life measure, behavior state, is that only two states, awake/alert and interact, are considered optimum for learning (Guess, Roberts, & Guy, 1999). This assumption might be questioned in light of observations of Lucy, a child with Rett Syndrome. As is characteristic of children with Rett Syndrome, Lucy moved her hands almost continually in repetitive patterns. However, it did appear that she discerned something was different about her environment when Soundbeam was introduced as her leg movements which activated the instrument increased as did her indices of happiness. Perhaps a preferred state for children whose stereotypies are considered "organically based" (Evans & Meyer, 1999) may include the co-occurrence of those stereotypies with other alert behaviors.

The second quality of life measure, indices of happiness, may also need further examination of its construct validity. As the protocol requires the user to count smiles, one must also think about other purposes of smiles. Smiles can serve other purposes than to express happiness. Green and Reid (1996) discount the possibility that individuals with SMD smile merely to conform to social norms. However, smiles can also be used to initiate interactions with others. Both participants in this study seemed to use smiles for the social purposes. A smile may be an effective method for SMD children to draw positive attention and social interaction from others. The participants in this study might have smiled at times, especially in the beginning of the study, to try and engage the investigator in a social interaction rather than to express happiness. The necessity of the investigator to remain in close proximity to the children in order to code behavior state might have led to social smiling to confound this measure.

Finally, a concern could be expressed about the third quality of life measure, the use of movement counts as an indicator of learning cause and effect relationships. Movements of the participants in this study to alleviate physical discomfort or express anger could all have been counted as movement intervals. These types of movements, of course, would not reflect the participants' understanding of the contingency. Also, the participants could have learned the contingency but not consistently expressed this understanding by increasing their movements. Satiation with the musical stimulation or simple physical fatigue could have resulted in a reduction of movements would confound these counts as a construct for understanding the concept of cause and effect.

Recommendations for Further Research

Further research on Soundbeam as an intervention to provide contingent stimulation and further research on the use of quality of life measures would serve to clarify and extend the findings of this study. The effectiveness of Soundbeam on quality of life factors could be further explored in studies with participants who have different characteristics, use Soundbeam in different ways, or make direct comparisons of Soundbeam to other types of contingent stimulation interventions.

Providing Soundbeam experiences to infants with SMD may result in a much larger change in quality of life assessments than was demonstrated in this study. Guess, Roberts, and Rues (2002) report that behavior state profiles stabilize around three years of age for children with SMD. The provision of the Soundbeam contingency experience to children younger than 3 years may have more of an effect as a control parameter for changing and improving poor behavior state profiles than children who receive the contingency experience when they are older.

Soundbeam may also have a greater effect on improving state profiles of children who exhibit different behavior state profiles than the participants in this study. Studies that examine its effect on children with high incidences of drowse or daze states or children who are alert but rarely interact with the environment would be informative.

A study that directly compares the effectiveness of Soundbeam to other types of contingency experiences such as switch activated toys would provide teachers and caregivers with specific data on the relative effectiveness of this device. Comparisons of how quickly children with SMD become satiated with the output or how much instruction is needed in order to experience contingent responses would provide important information to teachers and caregivers who are considering obtaining these types of devices.

As quality of life is emerging as an important framework in which to evaluate interventions designed for individuals with SMD, further evaluation and use of the quality of life assessments would be useful. Possible changes to reflect more accurate construct validity, adaptation of the protocols for use by practitioners and the use of these assessments to evaluate a variety of interventions would be useful.

Single subject studies on interventions for SMD individuals that report means, standard deviations, and number of measures taken in each phase would be extremely helpful as ranges of obtained effect sizes could be calculated and compared to other studies of similar interventions. One reason for the tentativeness of the conclusions reached in this study was the absence of literature on effect sizes for single subject studies with SMD participants. Although meta-analyses of between-group studies of interventions in the social sciences and medical fields provide a context in which to evaluate meaningful effect sizes (Lipsey, 1990; McCartney & Rosenthal, 2000), the absence of such information in the literature of interventions for SMD individuals leaves no basis for comparison. In addition, studies that attempted to correlate obtained effect sizes with other measures of improvement such as subjective impressions of caretakers or objective measures such as muscle range of motion would be important to help determine what the magnitude of "meaningful" effect are for this population.

Summary

A single subject multiple baseline design with was used to evaluate the effect of providing contingent musical stimulation to voluntary movements on three quality of life measures in 2 participants, aged 4 and 6 years, with severe multiple disabilities. The intervention, provided by a movement sensor called Soundbeam, consisted of providing music both contingent and noncontingent to the girls' voluntary movements in addition to access to their preferred leisure activity. All experimental sessions were conducted the participants' homes over a 13 week period.

Different results were obtained for the 2 participants. One participant exhibited a slight decrease observed happiness indices when the contingent component of the intervention was presented. The other measures of percentage of preferred state and level of movement did not change.

The second participant demonstrated a decrease in percentage of preferred state intervals and an increase in observed happiness indices and voluntary movements after the introduction of the intervention. These changes were maintained for the remainder of the experiment.

One conclusion was that the quality of life assessments used can effectively detect change even over the relatively short term of this experiment. The construct validity of these assessments may need further evaluation.

It was also concluded that further study is needed before Soundbeam can be recommended as an effective intervention to improve the three quality of life factors measured in young children with severe disability. Further research on Soundbeam with SMD children of different ages and with different behavior state profiles was recommended.

In addition, this study demonstrated the need for the development of a database on obtained effect sizes in single subject research on interventions for individuals with severe multiple disability. A comparison of effect sizes across studies would provide both a context in which to assess progress and a method of synthesizing the effectiveness of various interventions.

APPENDICES

Appendix A

Informed Consent

MICHIGAN STATE
UNIVERSITY

February 3, 2004

TO: Gail DUMMER
132 IM Sports Circle
MSU

RE: **IRB# 03-042** CATEGORY: FULL REVIEW

APPROVAL DATE: February 3, 2003
EXPIRATION DATE: January 3, 2004

TITLE: THE EFFECT OF CONTINGENT AUDITORY STIMULATION OF SELF-INITIATED MOVEMENT ON THREE QUALITY OF LIFE FACTORS IN YOUNG CHILDREN WITH SEVERE MULTIPLE DISABILITIES

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete and I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the **UCRIHS approved this project.**

RENEWALS: UCRIHS approval is valid until the expiration date listed above. Projects continuing beyond this date must be renewed with the renewal form. A maximum of four such expedited renewals are possible. Investigators wishing to continue a project beyond that time need to submit a 5-year application for a complete review.
REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please include a revision form with the renewal. To revise an approved protocol at any other time during the year, send your written request with an attached revision cover sheet to the UCRIHS Chair, requesting revised approval and referencing the project's IRB# and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.
PROBLEMS/CHANGES: Should either of the following arise during the course of the work, notify UCRIHS promptly: 1) problems (unexpected side effects, complaints, etc.) involving human subjects or 2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of further assistance, please contact us at (517) 355-2180 or via email: UCRIHS@msu.edu. Please note that all UCRIHS forms are located on the web: http://www.msu.edu/user/ucrihs

Sincerely,

Ashir Kumar, M.D.
UCRIHS Chair

AK: jm

cc: Cathy McQuillan
4113 Kenzie
Jackson, MI 49201

OFFICE OF
RESEARCH ETHICS AND STANDARDS

University Committee on Research Involving Human Subjects

Michigan State University
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Web: www.msu.edu/user/ucrihs
E-Mail: ucrihs@msu.edu

The Michigan State University IDEA is Institutional Diversity: Excellence in Action

MSU is an affirmative-action, equal-opportunity institution

Consent Form for Participation in the Study

The Effect of Contingent Auditory Stimulation on Three Quality of Life Measures in Young Children with Severe Multiple Disabilities

Dear Parent or Guardian:

My name is Cathy McQuillan and I am a doctoral candidate in special education at Michigan State University. I will be conducting a research study for my dissertation that involves young children with severe multiple disabilities. The purpose of this letter is to describe the study and invite your child to participate.

What is the purpose of the study?

One reason that children with severe disabilities may have difficulty learning is that it is hard for them to play with toys or participate in other learning activities by themselves. Several computer technologies have been developed that may make it easier for children with severe disabilities to "make something happen" by themselves. For example, you may be familiar with toys or devices that can be started by the child when he or she presses a switch.

The purpose of this study is to see whether a type of technology called Soundbeam may help children with severe disabilities stay alert, help them learn what happens when they make movements, and provide them with a fun way to play by themselves. Soundbeam is a musical instrument that is activated by movement only. It has an ultrasonic sensor that is connected to an electronic keyboard. Any movement in the sensor beam causes the keyboard to play. Some pictures of children using the Soundbeam equipment are on the last page of this letter.

Soundbeam is being used in many schools and learning centers in over 20 countries. There has been some research done about how effective this type of equipment is and I would like to add to that research.

How much time will the study take?

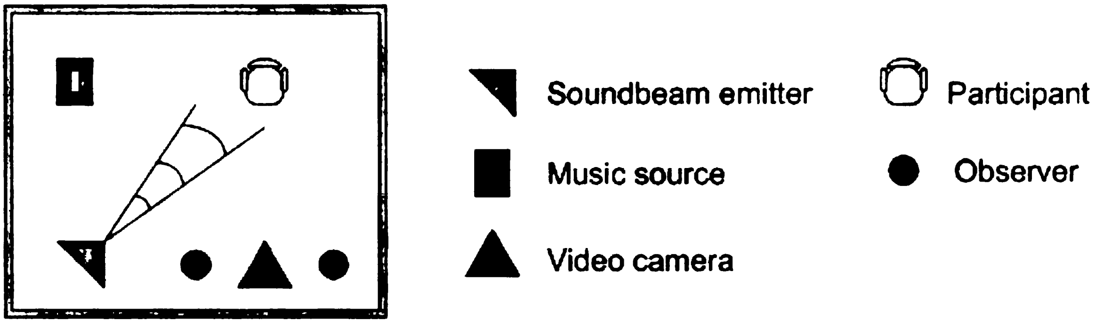
A child who participates in the study will be visited by me three times a week at home for 13 weeks in a row for a total of 39 visits. During these visits, I will bring the Soundbeam equipment, set it up and observe and videotape your child playing for 20 minutes. The total time of each visit would be about 30-40 minutes.

I would arrange a time to visit your home after school or in the evening that would be mutually agreeable to you and me. I would visit at the same time and on the same days of the week (for example at 4:30 on Monday, Wednesday and Friday.)

What happens during a visit?

I would ask you to choose a place in your home where I could set up equipment for the visits. The place should be a quiet area where the child's activity wouldn't interfere with normal family routines. You may observe all of the sessions if you wish.

During each visit the following things will happen. I will first set up the Soundbeam, your child's toys and the video camera in the area of the home you have selected. Then you and I will position the child in his/her wheel chair or seating system. The arrangement of equipment and observers will look like this.



There will be three types of sessions. During the first few sessions, we will give your child his/her favorite toys to play with. During the later sessions, the child will still have his favorite toys to play with, but will also have an opportunity to activate Soundbeam with his/her movements or will have an opportunity to listen to some musical output from the keyboard that does not depend on his/her movements.

During all of the sessions I will be watching your child and using a checklist to note how alert he or she is. I will also bring a second person called my "research assistant" to some of the sessions who will also observe your child and follow the same checklist. Later, I'll look at both checklists to see if our observations match. I will videotape the sessions so that after I've complete all my visits, I can review the tapes to see if the child seemed to enjoy the sessions and to record how much he/she moved during each of the sessions. At the end of each session I will ask you some questions your child's previous activities and mood before my visit.

What kind of information is gained from this study?

I will compare how alert the child was, how much the child moved and how much the child seemed to enjoy the activity across these three types of sessions. These comparisons may tell me how useful a movement sensor such as Soundbeam is to help children with severe disabilities learn and have fun.

Will children who participate in the study benefit in any way?

Children with severe multiple disabilities often don't have many chances to control things around them or "make things happen" by their own movements. There have been many reports by teachers and researchers that when children with severe multiple disabilities have an opportunity to use their movements to make music with the Soundbeam equipment, that they seem to learn better control of their movements and often seem to be happy while they use it. Children in this study may experience similar increases in motor control and enjoyment.

Are there any risks to children who participate in the study?

There are no physical risks to your child. The Soundbeam apparatus emits ultrasound beams toward the location in which the child is sitting. Any interruption to those beams caused by the child's movements is rewarded with contingent music feedback. Soundbeam has been used in over 1000 schools for the past ten years and no ill effects have been reported. Soundbeam was developed especially for individuals with severe multiple disabilities and is available for purchase from adaptive equipment catalogs.

In order to ensure that your child does not get uncomfortable in one position, we will only position your child in an upright position in his/her wheelchair or seating system for 20 minutes. With your permission, I will talk with your child's physical therapist to see if there are any concerns about positioning your child.

Your child may become disappointed when he/she no longer has a chance to play with Soundbeam after the study is over. For that reason, I will place the Soundbeam at your child's school so that your child can continue to use it there.

What happens if the child doesn't like the sessions?

If you or I feel that the child is not comfortable or does not want to continue the session, we will stop the session for the day.

Does it cost any thing to participate in the study?

No, there are no costs to participate.

How will the information from the study be used and how will our family and child's privacy be protected?

I will use information from my observations and the videotapes to write my dissertation, and possibly, to prepare published articles and/or educational presentations. I will keep the videotapes and written information in my immediate possession, a locked vehicle or in a locked file cabinet in my home office. I will keep these materials in my possession until all research publications and presentations have been completed and as required by my university. Then, the videotapes and written information will be destroyed.

Your child will be described in my dissertation and in any subsequent articles or presentations but his/her real name, school and city of residence will not be revealed. I will ask you to give me a pseudonym or "made up" name to use when describing your child. The only people who know the identity of the children and location of the study will be me, your child's school principal, classroom teacher, physical therapist, the research assistant, my university advisor (Dr. Gail Dummer), and members of my dissertation committee (Drs. David Stewart, Cynthia Okolo, and Tim Stocks).

In order to accurately describe your child I will ask you to allow me to review your child's school record in order to give your child's medical diagnosis, educational testing results and current educational goals in my written descriptions. When this type of description is provided in reports, it helps the readers (such as other teachers, researchers and parents) determine if the results that I report might apply to the children they are working with.

I would like to use short video clips of the children in the study to show in educational presentations after my dissertation is complete. Video clips often help people understand the information that is being presented. You do not have to allow me to use the clips in order for your child to participate in the study. If you do agree to allow me to use the clips for a presentation, I will ask you to review the clips and then sign a separate consent form before each presentation. An example of this separate consent form is attached to the end of this letter.

Your privacy and your child's privacy will be protected to the maximum extent allowable by law.

What happens if parents choose not to have their child participate in this study?

Participation in this study is entirely voluntary. If you choose not to participate, this does not affect your child's educational opportunities and current school program at all. Soundbeam will be placed at your child's school after the study and perhaps your child would like to try it then.

What happens if the parents and child start to participate in the study but then later change their minds and don't want to participate any more?

You may tell me at any time that you don't want to continue in the study and we will stop the visits. The information I've collected until then may or may not be used for my dissertation, depending upon the number of sessions completed. If you decide to stop participating, this will have no effect on your child's current educational plan.

Who should parents contact if they have questions, now or in the future?

If you have any questions about this study now, or in the future you may contact me (Cathy McQuillan) or my advisor (Gail Dummer):

Cathy McQuillan
Phone (517) 784-9287
Fax (517) 768-8148
E-mail mcquill1@msu.edu
Address 4113 Kenzie
Jackson, MI 49201

Dr. Gail M. Dummer
Phone (517) 355-4744
Fax (517) 353-2944
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Address 132 IM Sports Circle
Department of Kinesiology
Michigan State University
East Lansing, MI 48824

If you have questions or concerns regarding your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact Dr. Ashir Kumar, anonymously if you wish:

Ashir Kumar, M.D.
Chair of the University Committee on Research Involving Human Subjects (UCRIHS)
Phone (517) 355-2180
Fax (517) 432-4503
E-mail ucrihs@msu.edu
Address 202 Olds Hall
East Lansing, MI 48824

What should parents do if they think they might like their child to participate in this study?

I will be contacting you shortly to see if you are interested. If you think you might be interested we will arrange a meeting. I will demonstrate Soundbeam for you, we will talk about all of the information in this letter and I'll answer any questions you have. Then, if you would like to participate, I will obtain your signatures on the following page of this letter.

Sincerely,

Cathy McQuillan
Doctoral Student
Department of CEPSE
College of Education
Michigan State University

Appendix B

Coding Protocols

Behavior State

(Guess, Roberts, & Rues, 2001; Guess, Roberts, Siegel-Causey, & Rues, 1995; Roberts, 1992)

Directions to Coder

Begin auditory tape. A countdown will begin to Code 1. At the cue, begin observing the child for the five- second interval. During the five- second interval, it is helpful to tap out 5 beats, one for each second and note the observed state at each beat. For example, you may observe sleep, sleep, sleep, sleep, drowse during one interval as a child begins to change state. At the auditory cue "stop", look down at your sheet and circle the state the child displayed for majority of the interval. A quick note may also be jotted on the line below the box. If you are totally unsure about the observed state or missed the observation, make a diagonal slash through the box.

Look up and wait for the number cue to begin observing the next 5-second interval. Please make sure that the number of the interval you are coding matches the auditory cue.

Attached are three coding sheets for the 20 minute observation period consisting of 120 5-second intervals.

Abbreviations on coding sheet

SL	Sleep
DR	Drowse
DA	Daze
AW	Awake-inactive-alert
INT	Interact
ST	Stereotypy
CA	Crying, agitated
SI	Self injury
SEZ	Seizure, this is not considered a state but circle if one occurs during the interval

Child: ________________ Coder: ______________________ Page # 1
Date: ________________ Session # ___________

1
SL DR DA
AW INT
ST CA SI SEZ
____

2
SL DR DA
AW INT
ST CA SI SEZ
____

3
SL DR DA
AW INT
ST CA SI SEZ
____

4
SL DR DA
AW INT
ST CA SI SEZ
____

5
SL DR DA
AW INT
ST CA SI SEZ
____

6
SL DR DA
AW INT
ST CA SI SEZ
____

7
SL DR DA
AW INT
ST CA SI SEZ
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8
SL DR DA
AW INT
ST CA SI SEZ
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9
SL DR DA
AW INT
ST CA SI SEZ
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10.
SL DR DA
AW INT
ST CA SI SEZ
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11.
SL DR DA
AW INT
ST CA SI SEZ
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12.
SL DR DA
AW INT
ST CA SI SEZ
____

13.
SL DR DA
AW INT
ST CA SI SEZ
____

14.
SL DR DA
AW INT
ST CA SI SEZ
____

15.
SL DR DA
AW INT
ST CA SI SEZ
____

Happiness Indices

(Green & Reid, 1996)

Directions to Coder

Put videotape number on sheet. You will view a series of intervals where the participant has been previously identified as in a preferred state. The number of the interval will appear on a black screen immediately before each interval. Observe the entire 5-second interval for any happiness index displayed by the participant. A happiness index is defined as any behavioral indication of positive affect that is typically seen in individuals without disabilities. Examples are smiling and vocalizations that seem to express excitement or pleasure.

At the end of each interval the screen will go dark for 5 seconds. During this time, mark "yes" if at **any** time during the previous observed interval the child displayed at least one happiness index, mark "no" if no happiness index was observed. Then look back at the screen to observe the next interval.

Please make sure you mark the correct interval space. The total number of intervals will vary from videotape to videotape.

Voluntary Movements

Directions to Coder

Put videotape number on sheet. You will view a series of intervals where the participant has been previously identified as in a preferred state. The number of the interval will appear on a black screen immediately before each interval. Observe the entire 5-second interval for any voluntary movement made by the participant. A voluntary movement is defined differently for each participant. For Esther, a voluntary movement is any movement of her right arm or hand. For Lucy, a voluntary movement is any movement of her legs away from the footrest of her wheelchair.

At the end of each interval the screen will go dark for 5 seconds. During this time, mark "yes" if at **any** time during the previous observed interval the child displayed at least one voluntary movement. Mark "no if no voluntary movement was observed. Then look back at the screen to observe the next interval.

Please make sure you mark the correct interval space. The total number of intervals will vary from videotape to videotape.

Participant ____________ Coder_____________

Videotape # _____________

Total intervals coded_________

Interval	Happiness Index		Targeted Movement	
1.	Yes	No	Yes	No
2.	Yes	No	Yes	No
3.	Yes	No	Yes	No
4.	Yes	No	Yes	No
5.	Yes	No	Yes	No
6.	Yes	No	Yes	No
7.	Yes	No	Yes	No
8.	Yes	No	Yes	No
9.	Yes	No	Yes	No
10,	Yes	No	Yes	No
11.	Yes	No	Yes	No
12	Yes	No	Yes	No
13.	Yes	No	Yes	No
14,	Yes	No	Yes	No
15.	Yes	No	Yes	No
16.	Yes	No	Yes	No
17.	Yes	No	Yes	No
18.	Yes	No	Yes	No
19.	Yes	No	Yes	No
20.	Yes	No	Yes	No

Appendix C

Individual Protocols of Behavior State

Individual Behavior State Protocol

Participant *Esther*

Sleep
Teacher reports she never sleeps during the day unless ill, breathing sounds may be "rattley" and steady

Drowse
May be difficult to tell if her glasses are on, her head will be back against head rest

Daze
Relaxed body, eyes fixed, head not moving, sometimes appears "cross-eyed", sometimes appears to be looking up, sometimes hand can be "hooked" on toy

Awake/alert/inactive
Smiles, moves head, arches backward in chair, moving arms, swallowing, yawning, cooing, sounds

Interact
Touches toys- her hand or fingers must be moving or pushing against the hanging toy, touching her own arm, fingering her clothing

Stereotypy
Not observed

Crying/agitated
"Whiney vocalizations" for more than 3 counts, active grimacing

Self-injury
Not observed

Seizure
Mother says Esther's body will suddenly stiffen, she may cry out, then does not seem aware of surroundings at all

Individual Behavior State Protocol

Participant *Lucy*

Sleep
A very deep sleeper, her body will be totally relaxed, little movement

Drowse
Her head may be down on the armrest, may be lightly fingering her chin, eyes open and close very slowly

Daze
Not looking at the television screen or observers, glassy eyes, hands quiet in her lap

Awake/alert/inactive
No stereotypies, she often looks side to side, happy "buzzy" sounds, moving her legs, sucking on her pacifier, "whiney" vocalizations that don't last more than 3 counts

Interact
Grabbing at her bib before it comes to her mouth, scooping up her pacifier, rubbing her face or hair, fingering toy in her lap

Stereotypy
Hands poking at her mouth or chin, chewing her finger or leaving finger in her mouth and sucking, touching her tongue, chewing on her bib or wheel chair armrest

Crying/agitated
"whiney" vocalizations, loud cries, tears, banging her feet on footrest, throwing herself backward in wheelchair, wrinkles up face for more than 3 counts

Self-injury
Not observed

Seizure
Mother reports that Lucy has not had any seizures for over a year. Mom will monitor sessions for seizure activity.

Appendix D

Sample Session Log Sheets

Participant **Esther** Session **16**

Date *4/8/03 (Tuesday)*

Phase A **B** BC B

Co-rater **Yes** No

Normal routine
- Before session
  - Tube feeding at school at 11:30
  - PM school activities (story, video, music, circle time)
  - Toileting at 2:30 at school
  - Bus ride- Home at 3:10
  - Mother removes her AFOs
  - Wears Hensinger collar
  - Starts session as soon as she gets off bus at home
- During session
  - Hanging toys available on her right
  - Chair inclination at 110 degrees
  - Wears seatbelt, butterly harness; foot straps off
  - Soundbeam position and settings (when activated)
    - Sound source on her right, MIDI utilities= 11, 3/4 volume setting

Deviations from this routine
none

Conditions-
- Light- *average*
- Sound- *no street sounds, could hear brother crying in other room for about 4 seconds*
- Temperature-*felt a little cooler than usual, space heater was on*

Health notes
A few coughs, breathing sound " rattley" and loud but no meds needed at school

Esther's indications of assent or non-assent during this session
Cooing, smile , no indications of physical discomfort

Session notes, parent comments
Often arches to left when reaching for toys. Often pauses, smiles during the silence. Is she thinking about what she did? Smiles don't occur with movement but after the music stops. It might be too much for her to smile and move at the same time. She seems to get tired and need longer rest periods when her breathing is this loud. Mom said "I heard that nice music you were playing" when Esther was returned to living room- she smiled

Participant - **Lucy** Session **26**

Date *4/29/03 (Tuesday)*

Phase A B **BC** B

Co-rater Yes **No**

Normal routine

Lunch at school at 11:30
PM nap at school
Toileting at 2:30 at school
Bus ride; home at 3:20
Remove DAFOs and shoes
Watches videos until my arrival
Seat belt on, "chewy" bib, pacifier available on cord
Short chat with Mom while I set up equipment
Blues Clues video during session
Soundbeam position and settings (when activated)
  Sound source on her left, MIDI utilities= 11, 3/4 volume setting

Deviations from this routine

Stayed home from school (pinkeye). Mom said that Lucy hadn't slept for more than 30 minutes (about an hour less than her usual nap at school. Lunch was at 12:00, diaper change at 2:00

Mom put on Lucy's butterfly harness- didn't want her leaning too far forward and banging her head (she was very active yesterday).

Conditions-

Light- *Bright*
Sound- *My short conversation with mom about her pacifier during session. Phone rang once.*
Temperature- *Average*

Health notes

Pinkeye diagnosed this am at doctor. Lucy hasn't slept well but does not seem grumpy or unduly tired.

Lucy's indications of assent or non-assent during this session

Smiles, buzzy sounds. No protesting.

Session notes, parent comments

More movement today. Mom commented on how Lucy was watching me. "She likes the attention." Reactivity?? Is she performing for me or enjoying *the music/ This probably wouldn't be different across phases. One interaction with her when I had to re-attach pacifier back over harness.*

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