

1996

## **The Use of Communication Facilitators With Severely Brain Injured Non-Responsive Adults.**

Alisa Judith Mendoza

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THE USE OF COMMUNICATION FACILITATORS  
WITH SEVERELY BRAIN INJURED NON-RESPONSIVE ADULTS

A Dissertation

Submitted to the Graduate Faculty of the  
Louisiana State University and  
Agricultural and Mechanical College  
in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy

in

The Department of  
Communication Sciences and Disorders

by

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B.S., Florida State University, 1986  
M.S., Florida State University, 1988  
August 1996



**UMI Number: 9706347**

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## ACKNOWLEDGMENTS

Dr. Jane Collins, I am forever grateful that you ventured into the unknown and often strange world of my dissertation. Without your unwavering support, much needed insight, and cool head in a hotel fire, I never could have achieved this goal.

Dr. Jack Damico, you supported my efforts, fostered my interest in Ethnography and provided excellent guidance through all my research endeavors. You inspired and motivated me, from the beginning of my doctoral studies, with your kind words and incredible intellect. Always remember, "there is a tie that binds us to our homes".

Dr. Jack Cullen, thank you for your kindness, open mind, and for giving me the opportunity to experience St. Patrick's Day parades.

Dr. Sandy Damico and Dr. Judith Oxley, thanks for listening to my endless rambling and allowing me to work with the population and equipment that I love. I am proud to have been associated with both of you.

Thank you Adele, Herb and Mark, for the endless support. Sandra, Larry, Sally, Michael, and David, I never could have finished without your support and excellent care of Alex and then Jake.

Dr. Richardson, thank you for the wonderful anthropologic experiences you provided through your course

and the conference in South Carolina. I appreciate your patience and kindness over the last four years.

Travis, I know you are in a better place. A place where you can walk, play, eat and speak. Thank you and all the children who instilled in me the belief, "everybody can do something", and to the adults who reinforced this belief.

Dr. Lee, I thank you for more than I could possibly put into words. My mood-swings, fits, and post-partum depression would have driven a lesser man away. Your support and input over the last three years have been invaluable. I love you.

Alexander and Jacob, I would not have changed a minute of the last three years. You two are the most amazing and wonderful things to come out of my doctoral research.

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## ABSTRACT

Slow-to-Recover (STR) individuals are a subset of the neurologically impaired population who remain non-responsive for extended periods of time before beginning to demonstrate improvement in cognitive, communicative, or motor function. This investigation focuses on the development and implementation of a facilitator-based intervention program carried out with an STR brain injured adult residing in a long-term care facility. The model involved: 1) sensory stimulation techniques to increase responses to external stimuli, 2) augmentative techniques which enabled the subject to control his immediate environment and, 3) training of qualified residents within the facility to act as communication facilitators. Ethnographic procedures were employed in conjunction with quantitative measures over a six-month period to measure changes in the subject's functional abilities and describe overall changes in the communicative environment. Following eight weeks of communicative intervention, there were positive changes in the cognitive, motor, and communicative abilities of the subject that affected the interactive patterns and behavior of other participants. Results are discussed with regard to the contribution of each intervention technique in bringing about these changes.

## CHAPTER I: INTRODUCTION

This investigation evolved in response to a problem I encountered while supervising a clinical practicum in the Fall of 1991. My duties as a graduate assistant in the Division of Communication Disorders at the Louisiana State University included teaching and supervising students in the Augmentative Communication Clinic. This particular semester my student and I were confronted with a 60 year old stroke patient residing in a local nursing home. Non-verbal and severely physically impaired, this gentleman had no means of communicating or affecting his environment. Additionally, due to loss of mobility, he was confined to his room and isolated from the other residents of the long-term facility.

Two days a week the student and I provided the client access to "low tech" communication devices that enabled him to express his basic needs, wants and feelings. An example of a low technology device is the Dial Scan, by Don Johnston Inc., a large wheel and pointer with an overlay that contains pictures of desired objects or actions. Our client accessed the device by turning his head to activate a control interface, in this case a plate switch. While not immediately successful with the augmentative devices, we documented slow and steady cognitive gains and an increase in non-verbal signalling behavior over the course of the semester. We also discovered that the client was

motivated by an environmental control system that enabled him to control the television, lights, or radio.

The client's progress was heartening: however, we were faced with a dilemma at the end of each session. While we prepared to leave, packing up the augmentative devices and environmental controls, the man's eyes filled with tears. It seemed we had given him an hour of interaction and control and then had taken away both his communicative means and interactants. Furthermore, since his insurance did not cover speech-language services, he would no longer be provided therapy at the end of the semester, and there was little hope for continued use of assistive technology.

While at the nursing home, I noticed that there were residents throughout the facility expressing their boredom and searching for ways to occupy their time. It occurred to me that if the able-bodied residents were encouraged to interact with our non-verbal client on a regular basis, it might be beneficial for all. The more capable residents could even be trained in assistive technology to further facilitate verbal/non-verbal interactions. Consequently, the client would have the opportunity to communicate and the residents would be occupied with a meaningful activity.

My continued association with the Augmentative Communication Clinic brought me into contact with several other non-verbal, brain-injured nursing home residents of varying etiologies. While not all were profoundly

impaired, I was intrigued by those that appeared comatose, remaining non-responsive to the external environment for extended periods of time. These were the most challenging clients, often considered inappropriate candidates for augmentative systems. These individuals did not respond to traditional therapeutic techniques, and given their poor prognosis for recovery, were not usually referred by physicians for rehabilitative services. Consequently, with no communicative means and the lack of therapeutic intervention, they appeared to plateau or even decrease in their functional abilities. Clearly, the problems of the profoundly brain-injured population needed to be addressed and an alternative service delivery model developed to meet their needs.

My interest in adults with acquired neurological disorders led me to a paper by Ansell and Keenan (1989a), who had worked with patients they deemed "Slow to Recover" (STR). These profoundly brain-injured individuals remained non-responsive for longer than three months, demonstrated sleep-wake cycles, and were neither comatose nor in a persistent vegetative state (PVS). Ansell and Keenan (1989b) had developed the Western Neuro Sensory Stimulation Profile (WNSSP), an assessment instrument for STR patients that quantifies behavioral changes brought about through sensory stimulation. The researchers found that by implementing a sensory stimulation program with their STR

head-injured, stroke and anoxic patients, they could obtain responses that signalled some level of environmental awareness. Their rationale for employing sensory stimulation techniques was based on the premise that brain injury is a form of sensory deprivation and that structured multisensory input increases a STR patient's level of arousal and awareness. This, in turn, increases adaptive responses to environmental events.

I had become familiar with sensory stimulation for comatose patients in 1990 while attending a conference at the Madonna Center in Lincoln Nebraska. A multidisciplinary team at the center had experienced success with their comatose patients by merging sensory stimulation with augmentative communication techniques (Muehling, et al., 1990). The clinicians suggested that microswitch interfaces enabled comatose-like patients to control their environments via the activation of battery operated or electric appliances. Their patients began with incidental activation of the devices and progressed to more intentional responses. These techniques implemented along with the presentation of olfactory, auditory, visual, gustatory, and tactile stimuli appeared to elicit the greatest response.

Apart from Ansell and Keenen's work and that conducted at the Madonna Center, I found few references in the literature pertaining to sensory stimulation or

augmentative techniques with STR individuals. Given my interest in this population, the lack of research in the area, and the number of STR nursing home residents referred to the LSU Speech and Hearing Clinic for augmentative communication services, I decided to make it the focus of my dissertation. Additionally, based on my earlier discovery that STR patients were seldom eligible for rehabilitative services, it seemed the ideal opportunity to implement the facilitator-based model in the nursing home environment. Hence, the initial hypothesis of the study was conceived as follows: A model of communicative intervention focusing on sensory stimulation and augmentative techniques within a communication facilitator framework will effect positive changes in the cognitive, communicative, and motor functions of a STR brain injured adult.

While the study was designed to examine the effects of a facilitator-based service delivery model on subject behavior, I was aware that additional contextual factors would have to be considered. An earlier ethnographic investigation (Mendoza and Damico, 1991), revealed that the performance and rehabilitative potential of an adult with Locked-in-syndrome (LIS) was affected not only by physical condition, but intrinsic variables (i.e., depression, hopelessness, learned helplessness), and extrinsic factors (i.e., environmental deficits, lack of responsiveness on

the part of caregivers, unrealistic goals, poor prognosis for recovery). Therefore, the research methodology I selected would have to be sufficiently broad-based to allow for the description and analysis of not only the subject's responses, but the behaviors of all interactants, and effects of contextual variables.

To meet the descriptive and broad-based needs of the investigation, an ethnographic research methodology was employed along with Ansell and Keenan's (1989) quantitative assessment instrument, the WNNSP. Qualitative research methods carried out in conjunction with quantitative measures allowed for a rich, holistic description of not only the subject's cognitive, communicative, and motor behaviors, but all variables that were subject to change following implementation of the service delivery model. Ethnographic procedures were utilized for the following purposes: 1) to obtain an overview of the nursing home and determine the subject's role within the social situation prior to implementation of communicative intervention, 2) to describe the process of facilitator selection and training, 3) to identify emerging patterns of behavior between the subject and all participants, 4) to gather the perceptions, interpretations and expectations of caregivers, staff, residents, and professionals, and 5) to corroborate the findings of the WNNSP.



## CHAPTER 2: REVIEW OF THE LITERATURE

This chapter focuses on the unique rehabilitative needs of a profoundly impaired subset of the brain-injured population: Slow to Recover (STR) individuals. The discussion that follows includes a description of the STR population and the rehabilitative dilemmas they face. Three potentially effective therapeutic techniques are also described and discussed in terms of rationale and guidelines for application.

### Brain Injury and Recovery of Function

The leading causes of acquired neurological deficits in adults are head injury, which occurs over 400,000 times a year throughout the United States (Vogenthaler, 1987) and stroke, with approximately 500,000 new cases reported annually (Beukelman and Garrett, 1988). In addition to traumatic and vascular incidents, severe brain injury can occur secondary to infectious disease, metabolic disorder and drug overdose (Teasdale and Jennett, 1974). As the result of neurological damage, many individuals exhibit physical and intellectual impairments so severe they are unable to resume normal lives.

It has been reported that the majority of brain-injured patients demonstrate up to 90% of their improvement by six months post-onset (Block and Yuker, 1977). Jennett and Teasdale (1981) suggest that rapid recovery following severe brain injury most likely occurs on a biochemical

basis with restoration of neurotransmitter function, oxygenation, and perfusion to brain tissue. The mechanisms responsible for progressive recovery, however, have been the subject of much debate and speculation. In reviewing the various process approaches and the structural and physiological explanations offered in the literature, Bach-y-Rita (1980b) details five major mechanisms believed to be responsible for neurologic recovery: 1) recovery from neural shock (diaschisis), 2) neural substitution, 3) neural redundancy, 4) compensation, and 5) the unmasking of suppressed neural pathways. Licht (1973) suggests that the most likely explanations for progressive recovery from central nervous system (CNS) lesions are collateral sprouting or the sprouting of intact nerve fibers to occupy vacated synaptic sites, and the "unmasking" of previously existing pathways by modification of synaptic transmissions.

Regardless of the precise mechanism responsible for neurologic recovery, it is an ongoing and often lengthy process. Consequently, in addition to those who demonstrate the majority of their improvement within the first six months, there is a subset of the severely brain-injured population who remain non-responsive for extended periods of time before beginning to demonstrate any improvement. Ansell and Keenan (1989) refer to these individuals as "Slow to Recover" (STR).

### Slow-To-Recover Individuals

STR individuals are characterized by slow rate of change, reduced responsiveness and complex medical needs (Ansell and Keenan, 1989b). While often misdiagnosed as comatose or existing in a Persistent Vegetative State (PVS), STR individuals are neither. Comatose patients do not obey commands, give any comprehensible response, or open their eyes (Berrol, 1986). PVS patients "remain unresponsive and speechless until death" (Jennett and Bond, 1975). STR individuals, on the other hand, exhibit sleep-wake cycles, spontaneous eye opening or eye-opening in response to stimulation, and most significantly, do eventually demonstrate some improvement.

The difficulty lies in distinguishing STR individuals from comatose and PVS early on, and initial diagnosis often dictates subsequent rehabilitative efforts. Patients diagnosed as comatose are provided intensive stimulation while in the acute care setting; however, if they remain comatose following discharge, therapeutic efforts often cease. Therapy is not recommended for individuals perceived to be in a PVS as it is anticipated that they will not demonstrate improvement. Based on findings that many individuals initially diagnosed as PVS improve to the level of severe disability and in some cases even return to work, Berrol (1986) recommends that the term "persistent" not be added to "vegetative state" until one year after

injury. Consequently, it appears that the only means of determining whether a non-responsive patient will demonstrate some degree of functional recovery is to wait an interminable amount of time or implement some form of intervention.

Comatose and PVS individuals have been discussed extensively in the literature (Kaplan, 1988; Plum and Posner, 1980; Jennett et.al, 1979; Roberts, 1976); however, little research is available concerning STR individuals. Consequently, it is difficult to determine the incidence, course and extent of recovery, or viable intervention techniques for this population. Clearly, these issues must be explored if STR individuals are to have any hope for remediation.

#### Rehabilitative Options for STR Individuals

The issue of implementing therapeutic intervention with STR individuals remains problematic. Most brain-injured patients are initially seen in acute care settings and subsequently enter rehabilitative programs designed to increase cognitive and motor capabilities. Unfortunately, STR individuals do not respond to traditional rehabilitative techniques as they exhibit reduced responsiveness and profound motoric limitations. Due to initial lack of progress, ongoing medical needs and the perception of poor prognosis for recovery of function, many STR individuals are discharged from acute care hospitals

and transferred to long-term care facilities. The unusual, sometimes frightening, environment and lack of stimulation found in the nursing home coupled with severe neurological damage may lead to a state of sensory deprivation.

Moreover, STR individuals assume passive roles in long-term care facilities as they are no longer physically able to effect changes in their external environment or utilize conventional signals to serve communicative functions. The loss of motor function and lack of an interpretable response mode has serious psychological and social implications for the STR patient. Additionally, these individuals are seldom provided appropriate therapeutic intervention and are often isolated from others in the facility because they are non-ambulatory and require ongoing medical care. Optimum recovery of function and motivation to communicate is hampered by the lack of environmental stimulation, loss of control and lack of opportunity for peer interaction.

Despite a lack of focused attention, there are several therapeutic techniques which appear to hold promise for the STR population. There is evidence that indicates the cognitive and communicative abilities of minimally responsive individuals can be enhanced by an intervention program which incorporates 1) sensory stimulation to increase localized responses to external stimuli, 2) assistive technology which enables the individual to

control his physical environment, and 3) facilitator training focusing on optimizing interaction between the individual and communication partners.

### Sensory Stimulation

As previously noted, STR individuals do not respond to traditional rehabilitation programs which focus on restoration of oral speech, language, and higher level cognitive processes such as memory, reasoning and problem solving. Consequently, Ansell and Keenan (1989a) propose that STR individuals are candidates for sensory stimulation rather than intensive rehabilitation programs.

Sensory stimulation programs are designed to prevent sensory deprivation and provide structured input to maximize the brain-injured individual's ability to process and respond to stimuli (Phoebus, 1988). In terms of cognitive rehabilitation, the general goals of sensory stimulation are increased arousal and alertness, increased recognition of environmental events and an expanded range of adaptive responses (Smith and Ylvisaker, 1985). An adaptive response is defined as behavior of a more advanced, organized, flexible or productive nature than that which occurred before stimulation (Farber, 1982). Sensory stimulation techniques are designed to facilitate a severely brain-injured individual's transition from exhibiting minimal or generalized responses to external stimuli, to consistent, localized responses.

Anecdotal reports indicate that sensory stimulation programs facilitate the recovery of some comatose individuals (Phoebus, 1988); however, little research is available regarding the efficacy of this treatment with STR individuals. Despite the lack of evidence that sensory stimulation is effective for this population, support for implementation of these techniques is based on 1) the potentially damaging neurophysiologic effects of sensory deprivation, and 2) evidence related to the benefits of environmental enrichment.

#### Sensory Deprivation

Smith and Ylvisaker (1985) note that "in the absence of a stimulation program, a comatose or semi-comatose individual experiences severe sensory deprivation" (p.277). Moore (1980) defines sensory deprivation as "any change in the internal or external environment that deprives an organism of normal and necessary sensori-motor, re-afferent stimuli", and lists the following contributing variables:

"a) the isolation normally found in the sterile environment of an intensive care unit, private room or hospital, b) lack of familiar surroundings, c) separation from loved ones and visitors, d) lack of familiar sounds such as music, traffic, street sounds and vibration, e) the excessive use of prescribed drugs for sedation, f) interruptions to REM sleep, g) confinement to bed, h) changes in food and fluid, i) change in the air one breathes, and j) lack of movement" (p.70).

STR individuals placed in long-term care facilities are particularly vulnerable to sensory deprivation as they

experience most, if not all, of these precipitating factors.

Moore (1980) equates the effects of sensory deprivation on the nervous system to that of muscles deprived of normal function, with gradual loss of muscle tone and eventual atrophy of muscle fibers. He explains that "like the triceps brachii and the quadriceps muscles that are usually most susceptible to change resulting from disuse, the Reticular Activating System (RAS) undergoes comparable anatomical and physiological changes due to sensory deprivation" (p.71).

The RAS, a vital regulator of the CNS, is especially vulnerable to anesthetics, tranquilizers, pain medications, changes in sleep patterns and loss of stimuli necessary to keep the organism functioning as normally as possible. Functionally, the RAS is believed responsible for emotional tone (behavioral patterns), drives or motivations, short and long term memory storage and retrieval of knowledge or cognition (Ansell and Keenan, 1989a; Smith and Ylvisaker, 1985). Moore (1980) proposes that when a lesion of the nervous system is compounded with sensory deprivation the prognosis for recovery of function is poorer than when precautions are taken to prevent sensory deprivation.

In addition to the neurophysiologic effects of sensory deprivation, there are equally damaging affective changes. Goldberger (1969) reports that sensory deprivation is a



totally altered life situation that affects self-systems, defenses, fantasies, motivations, and cognitive and interpersonal stratagems. Thomson (1973), a nursing student who experienced sensory deprivation secondary to profound brain injury, reported that she experienced hallucinations, incoherence, hysteria, and emotional lability when confined to a hospital bed 24 hours a day. She also began believing that the hospital staff and significant others were conspiring against her. Leiderman (1964) examined the affective behaviors of hospitalized patients exposed to constant, unvarying sensory environments. The researcher reported that patients confined in tank-type respirators, body casts or traction exhibited transient psychotic-like symptoms (i.e., anxiety, delusions, visual, auditory and somesthetic hallucinations). Moreover, the psychotic state abated promptly with manipulation of the sensory environment (e.g. provision of a night-light, radio or television).

While there is a great deal of variation in individual responses, normal subjects exposed to artificial conditions of sensory deprivation exhibit a range of negative affective behaviors including boredom, restlessness, irritability, exaggerated emotional reactions, paranoia, changes in body image, lack of facial affect, speech impairments, fatigue and loss of motivation (Brownfield,

1972; Freedman, Grunebaum and Greenblatt, 1961; Zubek, 1969; Cohen et al., 1959, Bexton, Heron and Scott, 1954).

The interaction between neurophysiologic and affective changes resulting from sensory deprivation, and the deficits of an already damaged system impact negatively on prognosis for any degree of functional recovery. Clearly, if STR individuals are to have any hope for rehabilitation, steps must be taken to minimize the effects of sensory deprivation. Fortunately, even with severely involved individuals, the RAS can be stimulated to prevent excessive sensory deprivation. Farber (1982) postulates that the threshold of activation of reticular neurons may increase as the result of sensory deprivation, but suggests that controlled and structured sensory stimulation may lower the threshold of these reticular neurons resulting in increased cortical activation.

#### Environmental Enrichment

Controlled studies of sensory deprivation with brain-injured human subjects present moral and ethical problems; therefore, conclusions regarding the efficacy of enriched environments are drawn from other indirect evidence. A number of animal studies have established the value of rich sensory environments (Rosenzweig, 1980; Rosenzweig, 1966). Researchers utilize the terms "enriched", "standard" and "impoverished" environments primarily when studying animal behavior (Diamond, 1988). An enriched environmental

condition, for example, would be a large cage containing a variety of stimulus items or "toys" that could be seen, manipulated or explored. A standard environment would be a smaller cage with no special stimulation other than that designed to meet basic biological needs. Finally, an impoverished environment would be a small cage, limiting mobility and in which animals would be isolated without access to external stimuli.

There is evidence to support the contention that providing stimulation, above and beyond that required to meet biological needs, produces positive changes in nervous system structure and function, as well as facilitating learning and problem-solving skills. The findings of two extended studies indicate that the brains of enriched rats show positive changes in structure and function when compared to animals maintained in standard or impoverished environments (Diamond, 1988; Rosenzweig, 1980). Changes include increases in: a) cortical and hippocampal thickness, b) cortical weight, c) glial proliferation, d) dendritic branching, e) numbers of dendritic spines, f) total area of synaptic contacts, and g) average synaptic size and neurochemical activity. These results have been replicated in studies with cats, monkeys, squirrels, mice and gerbils (Renner & Rosenzweig, 1987). Enriched animals also demonstrate significantly greater learning, memory, and problem solving abilities than their impoverished

counterparts (Diamond, 1988). Based on the results he obtained from numerous animal deprivation studies, Rosenzweig (1980) concludes that "an enriched environment can be compared loosely to a therapy program and can compensate for certain brain lesions" (p.90).

Ansell and Keenan (1989a) suggest that facilities which provide sensory stimulation programs can be viewed as enriched environments when compared to those engaged only in maintaining a person's life. In terms of STR individuals, it would appear that environmental enrichment through carefully modulated sensory stimulation might accelerate the neural recovery process and at the same time inhibit the long-term negative effects of extended inactivity and sensory deprivation. Moreover, Phoebus (1988) suggests that sensory stimulation programs "allow for frequent monitoring of individuals so that the ability to respond to a small, but functional extent, does not go unnoticed".

#### Guidelines For Implementation of Sensory Stimulation

The actual procedures utilized during sensory stimulation activities vary based on the needs of the individual; however, the following general guidelines have been derived from the literature: 1) stimuli are presented on the basis of the phylogenetic sequence of brain development, 2) subcortical activities are targeted before cortical activities, 3) the program begins with unisensory

and progresses to multisensory stimulation and, 4) stimuli should be meaningful and based on past preferences.

#### Phylogenetic Sequence

The rationale for targeting phylogenetically older senses is based on the work of Moore (1980), who suggests that a sensory stimulation program begin with the primitive senses and progress to the neo-systems while increasing the complexity of sensory stimuli. Moore explains that the neo-components of the brain are usually most vulnerable to trauma and are the last to recover because they are principally lateralized and less plastic. Phylogenetically older systems, on the other hand, appear to be more plastic, are bilaterally organized and redundant, and are endowed with a greater number of polysensory synaptic connections, feedback circuits, commissural fibers and genetic memory or pre-programmed reflex/responses. Thus stimulation initially focuses on the senses of touch, kinesthesia, olfaction, and gustation before progressing to more cortically oriented systems of vision and hearing.

#### Subcortical Before Cortical

In addition to targeting phylogenetically older senses, an initial emphasis is placed on subcortical activity with cortical commands used later in treatment when an individual shows consistent adaptive responses (Farber, 1982). According to Moore (1980), older CNS systems cannot be reawakened by utilizing techniques such

as walking, dressing, eating, writing and speaking. These activities require a degree of conscious effort and are more applicable for rehabilitating the neo-systems. These older systems need to be tapped and reinforced in the manner in which they once functioned, by utilizing more primitive kinds of stimuli such as vibration, touch, olfaction, pressure and resistance. Moore (1980) concludes that sensory stimulation techniques target the basic needs of the brain-injured individual's nervous system (i.e., the vibratory touch pressure receptors and special senses of smell, hearing, and movement), much like the sensory input provided to infants and young children.

#### Isolating Modalities

It is recommended that in the early stages of sensory stimulation it is best to isolate one sensory modality so as not to "overload" the system (Smith and Ylvisaker, 1985; Farber, 1982; Moore, 1980). Phoebus (1988) recommends controlling the environment so there are as few distractions as possible, applying one stimulus at a time and observing any response that occurs. If a response is observed, she suggests attempting to elicit the same response with a different stimulus. Stimulation should be attempted in all five senses and should vary in nature and intensity to maximize the possibility of increasing arousal. Initial reflexive responses to stimuli may gradually be brought under voluntary control. For example,

auditory and verbal stimulation progress from presentation of non-speech sounds to more finely discriminated speech. Multisensory stimuli may be introduced as the individual begins demonstrating increased awareness and processing ability. Phoebus concludes that once consistent responses begin to emerge, the speech-language pathologist may direct the program toward the attainment of more functional goals, such as the establishment of a "yes-no" communication system.

#### Meaningful Activities

Sensory stimulation techniques should be meaningful, based on past preferences and as appropriate or natural as possible in order to productively shape adaptive response formation. Moore (1980) suggests that in order for learning to occur in the nervous system, "that which is learned must have some meaning or degree of importance to the organism that is doing the learning" (p.72). He notes that in any therapeutic situation, the individual needs to understand why something is being done or they are engaged in a certain activity, and the more closely the event or learning situation parallels or is related in some way to survival mechanisms the better one learns. Phoebus (1988) notes that stimuli that have emotional significance to the patient may be most likely to elicit response.

Ansell and Keenan (1989a) provide several examples of stimulation treatments based on the above guidelines:

1. Presenting tactile/gustatory stimulation to the lips via flavored ice popsicles to facilitate purposeful oral movement and awareness/recognition of flavors and temperature.
2. Providing orientation information including greeting them by name, telling the day, date, time, name of the facility, reason why he/she is there and length of time he/she has been there.
3. Presenting visual stimuli (e.g. snow globe, pinwheel) to engage the individuals attention and facilitate tracking.
4. Presenting multisensory stimulation to facilitate auditory comprehension, such as, putting a "nerf" ball in the individual's hand and aiding in squeezing while presenting the auditory stimulus, "squeeze the ball".

The progression of therapy and types of sensory stimuli vary based on the individual's responses and past preferences; however, it is theorized that environmental enrichment via structured sensory stimulation may facilitate the emergence of adaptive responses, thus enabling the STR individual to access a variety of augmentative techniques.

#### Augmentative Techniques

Sensory stimulation programs are designed to address various aspects of primitive cognitive function such as awareness, attention and adaptive responses to sensory



stimuli. There is, however, an additional need to take advantage of any residual capabilities (i.e., motor control, sensory skills) the STR individual retains in order to eventually re-establish expressive communication. The prognosis for substantial recovery of oral speech is poor for this population; however, alternative systems have been developed to augment communication.

The field of Augmentative/Alternative Communication (AAC), a subdiscipline of speech pathology, has evolved to meet the needs of many non-speaking individuals through both sophisticated and simple communication devices and systems. Unfortunately, STR individuals are often perceived as poor candidates for communication augmentation due to attention and perceptual deficits, and lack of consistent motor response. It is true, at least initially, that STR individuals lack the cognitive and motor capabilities necessary to access sophisticated devices; however, simple technologies are available to effect changes in communicative behaviors. These appear to hold promise for the STR population. "Simple" technology is a generic term describing enabling devices which allow individuals with severe disabilities to independently control objects and external events. A microswitch or control interface is a simple electromechanical device which the AAC user contacts with a body movement to activate any battery operated or electrical appliance. For

example, the STR individual blinks his eye to access an infra-red switch, which in turn activates a radio, television set or tape-player. Microswitch applications are designed to ensure that individuals with severe disabilities can employ even subtle and infrequent movements within their voluntary motor repertoire and temporal limitations to act reliably upon their environments (Schweigart, 1989).

Beukelman and Garrett (1988) suggest that, when assessing the residual capabilities of potential AAC users, it is essential to note if the individual demonstrates the minimal capability to utilize an alternative communication technique or strategy. In the case of the STR individual, it may be necessary to elicit and shape minimal responses which can subsequently be utilized to access simple technology. Microswitch technology is perhaps the only viable means through the STR individual can functionally utilize minimal motor responses (e.g. eye-blinks, head turn), to control various aspects of his environment. It is essential to provide access to enabling devices early on, as the inability to effect changes in the environment or behaviors of others can contribute to a state of learned helplessness.

### Learned Helplessness

Seligman's (1975) model of learned helplessness is based on the premise that an individual who senses a loss

of control over his immediate surroundings may, over time, experience a lack of motivation to attempt to effect environmental changes. The ensuing sense of helplessness, a psychological state that frequently results when events are uncontrollable, may impede future progress. The symptoms of learned helplessness include lowered initiation of voluntary responses, negative cognitive set, lowered aggression, loss of appetite, and negative physiological changes. As an end result, learned helplessness may lead to emotional disturbance or depression (Roessler and Bolton, 1978; Seligman, 1975).

According to Seligman (1975), the incentive to initiate voluntary responses has one primary source: the expectation that responding will produce change. In the absence of this incentive, voluntary responding will decrease in likelihood. Learned helplessness is caused by learning that responding is independent of reinforcement. Seligman (1975) concludes that the discovery of "synchrony" between one's own behavior and environmental outcomes must occur if this feeling of helplessness is to be avoided.

In order to prevent or diminish the effects of learned helplessness, the STR individual should be provided a means by which to control certain aspects of his environment early on. However, the existence of severe cognitive and sensory impairments may necessitate re-establishment of "contingency awareness".

### Contingency Awareness

Seligman (1975) proposes that once a man or animal has had experience with uncontrollability he has difficulty recognizing that his response is effective even when it has been successful. The STR individual experiences a profound lack of control from the onset of illness, in the hospital setting and particularly within the long-term care facility. Consequently, microswitch technology is initially utilized to re-establish the concept of contingency awareness, or the realization of the association between one's own behavior and environmental outcomes (Schweigart, 1989). This realization is crucial as intentional communication requires an awareness of the contingency between the expressive behaviors of the communicator and responsive outcomes of the social environment (Schweigart and Rowland, 1992).

A number of researchers have employed simple technology to investigate or establish contingency awareness in children and adolescents with severe/multiple impairments (Dunst, Cushing and Vance, 1985; Brinker, 1982; Accrino and Zuromski, 1978). In an early investigation, Watson and Ramey (1972) demonstrated that infants under three months of age, experiencing a "natural period of deprivation", could be trained to discern the contingent relationship between response and reinforcement. The researchers described an eight month old functioning at a

two-week-old level that demonstrated increased leg kicking with artificially mediated response contingent behavior. Haskett and Hollar (1978) utilized sensory stimuli (lights and music) as contingent reinforcement in a study with four youths, aged 9-17 years, exhibiting profound retardation and physical impairments. The individuals were required to depress a wooden lever in order to receive the sensory reinforcement. Results of the study revealed that three of the subjects learned to discriminate between response-dependent and response-independent behavior.

Schweigart (1989) suggests that contingency learning tasks that are restricted to non-social outcomes are insufficient to the development of social-communicative competence. In a case study involving a 7 year old child with multiple handicaps, Schweigart (1989) demonstrated that microswitch technology is more effective when object stimuli are paired with a contingent social response than when object stimuli are presented in isolation. In a more recent discussion of microtechnology, Schweigart and Rowland (1992) describe the Early Communication Process (ECP), an instructional sequence that they suggest bridges the gap between the establishment of social contingency awareness through microtechnology and the use of high technology devices for symbolic communication. The sequence is comprised of the following four levels:

Level I Gaining attention:

A single switch, similar to a call button, or a switch-activated tape recorder with a message such as "hey", may be utilized to obtain a response from another individual.

Level II Making requests and expressing interests:

A switch may be attached to a television or radio and, when activated by the individual, indicates interest in that object or activity.

Level III Making choices and expressing preferences using multiple switches:

Two switches may be presented, and the individual chooses between two objects or activities by activating the appropriate switch.

Level IV Making choices and expressing preferences using symbols and multiple switches:

The individual must interpret symbols or words placed upon multiple switches and subsequently activate the appropriate switch in order to obtain a desired object or engage in a preferred activity.

The ECP was developed as an instructional sequence for children with profound disabilities; however, with modifications to stimuli and reinforcement, it would appear to be a viable sequence in which to implement microtechnology with non-responsive adults.

It has been demonstrated that children and adolescents with profound cognitive and motoric disabilities have successfully increased target behaviors and gained awareness of control in the presence of contingent sensory and social stimuli controlled by different microswitch manipulations (Schweigart, 1989). Moreover, microswitch technology enables a profoundly disabled individual to actively participate in his own therapy program.

#### Active Participation

It is hypothesized that an intervention program which incorporates both sensory stimulation and augmentative techniques will prove beneficial to the STR individual as a potential AAC user. Whereas, the individual is primarily a passive participant during sensory stimulation activities, some degree of active participation is required to utilize microswitch technology. It has been reported that active participation and self-initiated purposeful activity result in greater cortical activation and integration and may also improve motivation (Will, 1977).

Based on a review of the literature pertaining to active participation, Ylvisaker and Smith (1985) conclude, "sensorimotor activity rather than passive sensory stimulation alone, may be necessary to produce desired stimulation effects". Moore (1980) identifies 10 components essential to therapeutic intervention with brain-injured adults, among them, active participation. He

states that active participation has repeatedly been shown superior to passive participation, and suggests that every effort should be made to get the brain-injured individual actively involved in the rehabilitation process.

Several researchers have suggested that microswitch technology can be effectively utilized to facilitate active participation by individuals in the early phases of recovery from brain injury. Smith and Ylvisaker (1985) report that head injured patients at their facility are assisted in performing familiar routines in order to facilitate active participation; however, for physically impaired patients, remote switch controls are utilized to operate adapted toys, radios, televisions and other devices.

Muehling et al. (1990), describe a switch activity hierarchy they find effective for facilitating active participation in patients emerging from coma;

1. Location of potential switch sites: The clinician Identifies sites of most frequent generalized or controllable movements (e.g. hands, fingers, head, knees, feet, mouth).
2. Match movement with switch characteristics: The clinician determines the amount of strength and displacement needed to activate various switches and considers other variables which facilitate and heighten the individual's awareness of switch



activation (e.g. auditory feedback, tactile features, visual salience, switch size).

3. Simple appliance control: The goals are to increase awareness of the environment via development of simple cause/effect connections, to increase initiation and decrease learned helplessness, and to shape generalized into localized responses.
4. Switch activated family message tapes: The goals are to elevate appliance activation skills into a more meaningful communication activity, to provide a way for the family to participate in treatment, and to encourage cognitive reorganization via presentation of reminiscence information.
5. Switch-activated conversational messages: The goals are to incorporate basic conversational participation into switch activities, to increase attentiveness and discrimination of auditory information.

These techniques can be applied to many potential AAC users; however, no research to date has been directed towards the use of microswitch technology with STR brain-injured adults.

#### Communication Facilitators

In order to facilitate cognitive recovery and re-establish communicative abilities, the STR individual is in need of a therapy program which incorporates sensory stimulation techniques and active participation via

microswitch technology. Unfortunately, the nature of the long-term care facility limits the availability of intervention agents.

#### STR Individuals as an Underserved Population

Medical personnel and insurance companies seldom provide referral or funding for sensory stimulation programs carried out by speech-language pathologists (Ansell and Keenan, 1989b). Moreover, in the rare cases that STR individuals are provided therapy, most speech-language pathologists are not trained in the use of augmentative techniques and subsequently rely on traditional approaches which are ineffective with this population (Ansell and Keenan, 1989a). Based on the cognitive/communicative needs of the STR population and lack of appropriate therapeutic services, consideration of an alternative service delivery model is warranted. A current trend within the field of communication disorders is the utilization of "support personnel" or individuals trained to assist therapists and clients in various clinical settings (Wervin, 1993).

In a recent discussion relating to the need for support personnel within the field of communication disorders, Wervin (1993) lists nine populations identified by the American Speech-Language-Hearing Association (ASHA) as underserved. Included among these populations are "individuals who have been institutionalized" and "head

injured persons with cognitive communicative handicaps". Wervin (1993) explains that "These populations and the settings in which they reside traditionally have had difficulty attracting clinicians". Subsequently, clinicians who choose to serve these populations are often faced with large caseloads and clients for whom traditional service delivery models are ineffective" (p.15). As a result, there is a high rate of clinical turnover within these settings and many individuals are left without services. Wervin (1993) explains that when underserved populations are without services an illusion develops that perhaps these services are not necessary, that the individuals are able to function without speech/language treatment, and that such services are a luxury reserved for patients or clients who are "easy" to work with. According to ASHA's (1988) Committee on Support Personnel, "there are diagnostic and treatment contexts, particularly those involving underserved populations, in which traditional service delivery models are difficult to employ. In these situations, support personnel are sometimes used as a means of providing clinical services that would otherwise be unavailable."

Researchers at the New Medico Rehabilitation Center of Wisconsin documented one of few studies involving support personnel trained to work with the brain-injured population (Wervin, 1992). Speech-language pathologists at the

facility identified and trained 16 rehabilitative aides to serve as speech-pathology assistants. Over a five week period, the aides were provided intensive classroom instruction, observed treatment sessions and participated in hands-on training with brain-injured clients. The aides subsequently provided support in the areas of cognitive and language rehabilitation, dysphagia treatment and computer activities. Two years following the inception of the project, eight of the original aides remained and five more were added. The impact on client progress included increases in clients' orientation and awareness, use of compensatory memory strategies, and generalization of treatment objectives in naturalistic settings. Moreover, the speech-pathology assistants were able to familiarize new clinicians with their caseloads and there was less clinical turnover among the assistants than there had been in the rehabilitative aide position. In addition to providing much needed services to underserved populations, support personnel can be trained to facilitate communicative abilities and effectively interact with non-verbal individuals.

#### Facilitator Training

Researchers within the field of AAC suggest that in order for communicative intervention to be optimally effective it should be dual-pronged, including 1) direct intervention with the client to assure communication access

and 2) intervention with the partners in the environment to ensure communication opportunities (Beukelman and Mirenda, 1987; Parnes, 1985). Consistent with this viewpoint, Light (1992) reports that professionals working with non-verbal individuals are now examining the role of facilitators, that is, significant others in the clients life (e.g. parents, teachers, teachers aides, friends, spouses) trained to provide communication opportunities and client support in a wide range of situations. Blackstone (1991) describes the role of communication facilitator as carrying out a myriad of activities related to interaction (e.g. positioning, reminding peers to do or not do something, instructing interactants to provide pause time). The goal in training communication facilitators is to help them develop the knowledge and skills necessary to support communicative development, that is, to empower them to assume some degree of responsibility in a non-speaking individual's communication program (Light, 1988). No studies to date have examined the efficacy of facilitator training with non-responsive individuals; however, there is evidence to support the use of communication facilitators based on research with other non-verbal populations.

Light (1988) notes that interactions between natural speakers and non-verbal individuals tend to be highly problematic, particularly in dyads where there is an inequality between interactants, (e.g. teacher-student,

parent-child, clinician-client, or staff-resident). In a comprehensive review of the literature, Light (1988) summarizes the findings of studies within the area of AAC focusing on interactions between natural and augmented speakers:

1. Most people who use AAC systems experience significant difficulties in their daily interactions (Light, 1988; Kraat, 1985) and have few opportunities to communicate with others (Calculator and Luchko, 1981; Kraat, 1979).
2. They are often pre-empted from opportunities to communicate by significant others in their environment who tend to anticipate their needs and wants (Halle, Baer, and Spradlin, 1981).
3. Turn-taking patterns with natural speakers tend to be highly asymmetrical, with natural speakers dominating the conversation and AAC users forfeiting their turns (Calculator and Dollaghan, 1982; Harris, 1982; Light, Collier and Parnes, 1985).
4. AAC users seldom initiate topics and primarily occupy the role of respondent (Calculator and Dollaghan, 1982).

The extreme difficulties AAC users experience in daily interactions have led various researchers within the area of AAC to examine the efficacy of instructing facilitators to support the communicative abilities of non-verbal

individuals. These studies have been carried out within various situational contexts (e.g. classrooms, residential facilities, home environments) and have focused primarily on the training of staff (Calculator and Dollaghan, 1982), and parents (Culp and Carlisle, 1988; Light, Collier and Parnes, 1985). A single-case study by Calculator and Luchko (1981) revealed that a 30 minute inservice for staff working with a non-verbal adolescent at a nursing home effected some basic changes in facilitator interaction strategies and resulted in positive changes in interactive patterns.

McNaughton and Light (1989) documented a case study of an adult AAC user with severe cognitive impairments residing in a group home. Twenty-five staff members were trained as facilitators and instructed in interaction techniques to foster communication. This training resulted in 1) the facilitators providing increased opportunities for client interaction, 2) the client meeting pre-specified goals for intervention, and 3) increased interactive participation by the client.

Culp and Carlisle (1988) reported on the efficacy of a communication-facilitator program involving child AAC users and their parents. Following five days at a summer camp in which the parents were trained to facilitate communication, the parents' interactions improved significantly in terms

of increased pause time, modified questions and following their child's lead.

The success of training staff and family members to act as communication facilitators has been established; however, it is often not a feasible solution when addressing the needs of the STR individual within the nursing home setting. STR individuals require frequent environmental stimulation and access to communicative opportunities. While some degree of staff training is desirable, the high rate of turnover within the long-term care facility would demand constant training of new staff members and provide little consistency within the STR individual's interactive environment. Moreover, it has been the researcher's experience that nursing staff and aides in long-term care facilities are employed solely to address medical needs and provide custodial care to residents. Because nursing homes are often understaffed, nurses and aides seldom have opportunities for extended social interaction.

Family members have also been trained as facilitators to promote generalization and optimize interaction with non-verbal individuals. Unfortunately, family members are seldom available to participate in ongoing intervention with brain-injured nursing home residents. While some degree of training to enhance communication is indicated for both staff and family members, they are not considered



viable candidates to act as primary communication facilitators.

### Peer Facilitators

It is suggested that communicative interactions are more meaningful when they occur between individuals of equal status (Block and Yuker, 1977); however, the majority of studies examining the effects of partner training have focused on unequal social relations. Light (1988) explains that AAC users have few opportunities for peer interaction; thus, in their daily environments they primarily interact with partners who are in higher status relationships. This finding is supported by researchers who report that non-speaking individuals in classrooms and residential settings interact primarily with professionals or staff members rather than peers (Harris, 1982; Calculator and Luchko, 1981; Kraat, 1979).

Despite the paucity of research, results of studies to date involving peer facilitators appear promising. Light et al. (1992) trained three facilitators to support the communicative abilities of two young AAC users residing in a group home. The women selected to act as facilitators included 1) a personal aide, 2) a supervisor at the group home, and 3) a friend of one of the AAC users. Following four one-hour sessions of instruction, there was an overall increase in the reciprocity of turn-taking and initiation within all dyads; however, there was individual variation

across facilitators and AAC users in terms of their response to instruction. Facilitator training had a more "dramatic" impact on interaction and generalization within the peer-AAC user dyad. The researchers speculate that training and interaction with the peer facilitator may have been more effective due to the length and nature of her relationship with the AAC user.

In terms of pre-requisite skills needed to support the communicative abilities of disabled and non-verbal individuals, it appears even preschoolers and elementary school children can be trained to act as communication facilitators. Venn et al. (1993), trained three preschool children to utilize a mand-model procedure with developmentally disabled counterparts, through direct instruction, role-playing, feedback and praise. The mand-model procedure, a milieu training strategy, entailed 1) the interactant noting the disabled child's focus of attention, 2) delivering a mand (non-yes/no request or command) related to that focus, 3) providing a short interval for response from the child, and 4) presenting a model of the desired communication skill if the response was not forthcoming. Results of the study indicated that the "preschool facilitators" learned to successfully utilize the complicated procedure with their developmentally disabled peers. Moreover, the disabled

preschoolers responded positively to the procedure and began interacting more effectively with other classmates.

Cassett-James (1989) examined the effects of peer facilitators on the communicative interactional skills of elementary school children using communication aids. Dyads were formed by age, interests and gender considerations. Following training, which included scripted instruction, modeling, role play and in-vivo practice, there were qualitative improvements documented in the interactions between the facilitators and their non-speaking peers. The facilitators demonstrated increased pause time which allowed the augmented speakers to respond and there was an increase in the number of conversational turns per interaction. Additionally, changes in the interactional patterns of facilitators were maintained over time and generalized to interaction with other non-speaking individuals. The peer facilitators were subsequently able to teach interactive strategies to fellow classmates.

Kohler and Strain (1990) report that peers have played a number of roles in the classroom setting, including serving as models, tutors and initiators of social interaction with their disabled counterparts. Odom, McConnell, and McEvoy, (1992) note that interactions between normally developing and disabled children 1) provide children who have disabilities with competent models, 2) facilitate skill acquisition, 3) promote

positive social interactions and friendship, 4) assist typically developing children in acquiring helping and altruistic behaviors and attitudes.

The benefits of peer interaction can be applied to a variety of populations and situational contexts; however little research has been devoted to studying interactional patterns between adult peers or the utilization of peer facilitators within institutional settings.

#### Guidelines for Training Communication Facilitators

Blackstone (1991) notes that most natural speakers are unprepared to interact with non-verbal or augmented speakers. Undoubtedly, attempts at interaction with non-responsive individuals prove substantially more difficult. Consequently, training sessions may initially focus on familiarizing facilitators with strategies to optimize their interactions with non-verbal individuals. For example, Blackstone (1991) suggests that natural speakers introduce themselves, provide pause time, interact at eye level, pay attention to facial expressions and gestures, and talk directly to non-verbal individual (p.6).

The actual procedures adopted during facilitator training vary depending on the specific situational context and learner characteristics; however, several general techniques have been derived from the literature. Types of instructional service delivery models include in-service, role play, modeling, demonstration, focused discussions,

simulated practice, and in-vivo training (Durgin et.al., 1993, Cassett-James, 1989; Light, 1988; Calculator and Luchko, 1983).

In addition to utilizing effective training techniques, it is essential to individualize instruction based on the characteristics of potential facilitators. Blackstone (1991) suggests that when dealing with adult learners, one should take into consideration mental, physical, social, cultural and emotional characteristics. This is particularly essential when training non-professionals to perform unfamiliar or complicated tasks. Additional guidelines gathered from the literature are based on adult learning theories: 1) content relevance is needed, 2) learner motivation should be high, 3) permit active participation in the learning process, 4) learning is facilitated by variety, 5) provide positive reinforcement, 6) personalize instruction, 7) use learner oriented strategies, 8) relate past experience to new learning, 9) let adults learn from each other, 10) build a climate conducive to learning, 11) allow flexibility for personal development, 12) don't start with "here's what you're doing wrong", 13) start with goals that will result in an impact they can see, and 14) be realistic (Blackstone, 1991; Strain, 1981). These strategies can be applied to facilitator training within a variety of situational contexts. In general, however, it would appear

that training programs which maximize participation, engage learners in direct practice of targeted skills, provide training and feedback in the natural setting and create a non-threatening learning environment would be most successful.

### Summary

STR individuals residing in long term care facilities are in need of intervention programs designed to increase cognitive/communicative functions, but are often ineligible for rehabilitative services. A review of the literature reveals that sensory stimulation may facilitate recovery of neural function in brain-injured adults; however few studies have been carried out with STR individuals. Moreover, it has been established that the use of microswitch technology provides severely disabled individuals a means of affecting their environments, yet no studies have addressed the use of simple technology with STR adults. Finally, research with AAC users indicates that partner training may optimize interactions and facilitate successful communication augmentation with STR individuals. The training of peer facilitators is considered an effective means of increasing opportunities for social interaction and providing therapeutic services to STR individuals who would otherwise do without.

This descriptive investigation examined the efficacy of utilizing sensory stimulation and augmentative

techniques within a communication facilitator framework to effect changes in a STR subject's communicative behaviors. Qualitative and quantitative research methods were employed for the purposes of data collection and analysis throughout all phases of the investigation. Qualified residents were selected from the population of a long-term care facility and subsequently trained to act as communication facilitators with the STR subject. It was hypothesized that the proposed model of intervention would enhance the STR subject's cognitive/communicative capabilities, thereby increasing his potential for successful communication augmentation.

### CHAPTER III: METHODOLOGY AND IMPLEMENTATION OF THE SERVICE DELIVERY MODEL

Efficacy of the facilitator-based service delivery model was evaluated via the comparison of data collected during two phases of the study designated by the investigator as Pre-implementation and Post-implementation. The Pre-implementation phase (7/8/92-9/21/92) included subject selection, facilitator selection, and facilitator training. The post-implementation phase (9/22/92-12/6/92) consisted of eight weeks of facilitator-based communicative intervention.

Data collection and analysis procedures derived from ethnography, a qualitative methodology, were utilized from the onset of the investigation to describe subject behavior and explore contextual environmental or situational variables that affected all participants. Quantitative measures, specifically an assessment instrument developed for the STR population, enabled the investigator to gather baseline data prior to implementation of the service delivery model and to document, on a weekly basis, changes in specific aspects of the subject's adaptive responses to sensory stimulation and augmentative techniques.

This chapter begins with an overview of the general principles and advantages of ethnographic methodology. Next, subject selection and the specific data collection and analysis procedures employed throughout the investigation are discussed. The final section of this



chapter details the processes of facilitator selection and training, and implementation of communicative intervention.

### Overview of Ethnography

Ethnography is a descriptive approach to research that originated in the field of anthropology over a century ago. Early ethnographic efforts were directed primarily toward collecting and cataloguing detailed information about primitive societies (Kovarsky and Crago, 1990). During the early twentieth century, however, ethnographers began devising more systematic data collection and analysis procedures that enabled them not only to describe, but interpret cultural phenomenon, and uncover the goals, intentions, and motivations underlying participant behavior. Because ethnography was a highly effective means of studying complex social phenomenon, anthropologists and more recently, researchers in other disciplines such as education, psychology, and sociology, began to employ the methodology to examine human affairs in their own societies.

Researchers in the field of communication disorders and sciences have traditionally relied on quantitative or scientific methodologies to explore communicative processes and disorders. Recently, however, there has been growing concern within the field as to the ecological validity of traditional practices which isolate communicative phenomenon and fail to account for the effects of "real-

world" or contextual variables (Kovarsky and Crago, 1990). Consequently, various investigators have begun to employ more naturalistic approaches, such as ethnography, to explore the efficacy of treatment programs (Damico, 1988), examine client/clinician interactions (Kovarsky, 1990), and identify variables which interfere with communicative competence (Crago, 1990).

#### Advantages of Ethnographic Methodology

The characteristics inherent in ethnographic methodology offer several advantages to the study of communication disorders. First, data collection is carried out in naturalistic settings which allows for the study of "communication-in-context". Rather than attempting to control for factors that may affect findings, the investigator scrutinizes contextual variables to determine their impact on the phenomenon under investigation. "Contextualization" lends insight into how and why people, activities, and physical surroundings interact with each other and influence cultural behavior. In terms of this study, the investigator was able to employ naturalistic methods to gain the subject's perspective of the communicative environment and to examine environmental and societal variables that impacted on his communicative competence and rehabilitative progress. Furthermore, because the investigator participated in the subject's daily activities, she was able to evaluate the effects of

her own interactions, reactions, motivations, and beliefs on participant behavior and data interpretations.

Another advantage to the employment of ethnographic procedures is the ongoing, almost simultaneous process of data collection and analysis. Rather than proceeding linearly, ethnographers collect, evaluate, and interpret data in a cyclical and interactive manner. At the beginning of the investigation, general descriptive questions are formulated to guide data collection procedures. As initial data are examined and interpreted, more specific research questions arise, leading to more focused investigation and analysis. The process continues as the investigator obtains a rich, authentic knowledge base and progressively focuses on phenomenon that are relevant and interesting to the research question.

Finally, in ethnography, theories are developed and defined through the analysis and interpretation of data, a methodology that has been referred to as "grounded theory" (Glaser and Strauss, 1967). The investigation is not guided by a priori assumptions, rather, the data themselves suggest possible explanations for observed behavior or events. Thus, the investigator does not need a significant base of empirical knowledge about the phenomenon under investigation before research is conducted. Successive data collections enable the researcher to progressively

test and prove (or disprove) hypotheses (Kovarsky and Crago, 1990).

#### Authenticity and Ethnographic Methodology

The goal of ethnographic research is "authenticity", a detailed, genuine, and consistent recording of cultural behavior and events. Ethnographers establish authenticity by relating multiple data sources in such a way as to counteract various possible threats to validity (Hammersley and Atkinson, 1989). This process has been referred to as "triangulation" (Agar, 1986). As suggested by Kovarsky and Crago (1990), the triangulation in the present study was by achieved studying a full range of events, collecting data in repeated occurrences of such events, and looking at events from a number of different perspectives and levels of the social system.

#### Specific Methodology

This section begins with a description of subject selection and quantitative methods followed by specific ethnographic data collection and analysis procedures. A discussion of facilitator selection, training, and communicative intervention follows. It should be noted that the names of the subject, his family members, staff, therapists, residents, and facilitators have been changed to protect the privacy and confidentiality of all participants.

### Subject Selection

The search for a Slow to Recover (STR), brain-injured subject began in May of 1992. At this time, the investigator contacted eight speech pathologists working in various rehabilitative settings. The therapists were informed about the nature of the investigation and asked if any of their past or present clients exhibited the following characteristics: 1) neurological impairment as the result of Traumatic Brain Injury, Stroke or Anoxia, 2) non-responsive, comatose or in a Persistent Vegetative State, 3) non-verbal, 4) severely physically impaired 5) under the age of 50, 6) more than 6 months post onset, 7) residing in a long-term care facility.

Two of the therapists were associated with individuals they felt met the criteria for STR. In order to maintain confidentiality, the therapists were asked to contact the caregivers to discuss the possibility of the brain-injured individuals participating in a research project. After determining that the families were interested, both clients were observed by the investigator and assessed within their natural environments.

The first individual, three years post-onset of a Traumatic Brain Injury, did not meet criteria for STR as he had established a primitive gestural system and was responsive to the environment. The second individual, Jason, 42, had suffered anoxia secondary to a heart attack

one year before. He was non-verbal, demonstrated minimal response to external stimuli, and was severely physically impaired. Jason met the criteria for STR, however, he was already provided with Speech-Language and Occupational therapy services at the long-term care facility where he resided. The staff speech-language pathologist described the existing therapy program, and it was determined that the techniques to be utilized for the facilitator-based model of communicative intervention were sufficiently different to warrant Jason's inclusion in the study. Additionally, he had demonstrated minimal progress, and the continuation of therapy was uncertain.

#### Quantitative Assessment of the Subject

Quantitative measures of the subject's cognitive and communicative status were obtained via the Western Neuro Sensory Stimulation Profile (WNSSP). The WNSSP was originally developed by Ansell and Keenan (1989) as a formal, objective measure of cognitive/communicative function in STR, severely impaired, head-injured patients. Ansell (1991), however, has since extended application of the instrument to STR stroke and anoxic encephalopathy patients. While normative data are based on the head-injured population, the authors propose that information obtained from the WNSSP can be utilized with other neurologically impaired populations to plan treatment,

monitor changes in performance, diagnose deficits, and study recovery patterns.

The WNSSP consists of 33 items designed to assess specific aspects of following behaviors; 1) arousal and attention, 2) expressive communication, and 3) response to auditory, visual, tactile and olfactory stimulation. Each item is scored using a multi-point system with higher scores indicating localized responses to stimuli and lower scores indicating minimal or generalized responses. The total score is the sum over 33 items with a maximum possible score of 113. The total score obtained is based on a continuum of responsiveness which correlates with levels II (generalized response) through V (confused-inappropriate response) of the Ranchos Los Amigos Hospital Scale of Cognitive Function (Malkmus, Booth and Kodimer, 1980).

The WNSSP was employed during the pre-implementation and post-implementation phases of this investigation to gather baseline data and quantify subsequent changes in subject behavior. The test was administered by the investigator when the subject was "awake" as indicated by eye-opening, postural adjustments, yawning or some degree of arousability. Ten testing sessions were video-recorded, transcribed, and scored over the course of the investigation (see Appendix A for scoring protocol). Upon completion of the project, videotaped sessions were again

viewed and scored by the investigator, to confirm the accuracy of initial results.

In addition to baseline and weekly administration of the WNSSP, the subject was evaluated by the staff occupational therapist (OT) prior to implementation of the service delivery model and following eight weeks of communicative intervention. The OT reported his results to the investigator who recorded them in fieldnotes. These data were then compared and contrasted with observational data and participant reports of the subject's motor status.

#### Ethnographic Methods

The ethnographic procedures employed over the course of this investigation were based on a modified version of Spradley's (1980) Developmental Research Sequence (DRS), a systematic approach to anthropologic fieldwork. Qualitative data collected during each stage of the investigation was evaluated for presence of recurring events, emerging patterns of interaction, and changes in participant behavior. The four levels of data manipulation included: 1) domain analysis, 2) taxonomic analysis, 3) componential analysis, and 4) theme analysis. As previously discussed, the employment of ethnographic procedures entailed a cyclic and almost simultaneous process of data collection and analysis. However, for the sake of clarity, a brief description of data collection



procedures is presented below, followed by a discussion of the four stages of data collection and analysis.

### Ethnographic Data Collection

In keeping with the techniques of triangulation, data was collected from multiple sources via the following procedures: 1) participant observation, 2) video and audio recording, 3) ethnographic interviewing, and 4) artifactual analysis.

#### Participant Observation

Participant observation refers to the anthropological practice of living among the research population, taking part in their activities, watching them do what they do, and asking questions when one does not understand what is happening. This process allows the investigator to check statements of attitude and value against actual behavior (Murphy, 1987). While unable to "live" among the population being studied, the researcher of this investigation "immersed" herself in the culture through extensive observation and a moderate level of participation in the daily activities of the brain-injured subject. The process of participant observation entailed a progressive narrowing of focus beginning with widespread observation of the entire cultural scene and ending with selective observations of specific behaviors and events.

During each observational session, key words, sentences, or phrases relating to the cultural scene were

recorded by the investigator in a notebook. These condensed notes were reviewed on a daily basis and then expanded to include more detailed descriptions of behaviors and events. Expanded "fieldnotes" were recorded in a large notebook, and supplemented with side-notes relating to the analysis and interpretation of data (Theoretical notes), the ethnographic process itself, and the investigators personal feelings including methodological problems, impressions, expectations, and breakthroughs. Appendix B contains the dates and nature of observational sessions.

#### Video-Recording

Following an initial period of broad-based observation, all sessions which took place in the subject's communicative environment were documented with a JVC GR-AX2 video-recording system. In order to remain unobtrusive, the investigator activated the compact videocamera prior to each session and placed it on a tripod in the corner of the subject's room. During administration of the WNSSP, however, the videocamera was placed at the foot of the subject's bed to ensure optimum recording of subtle motor or communicative responses. Over the course of the investigation, approximately 60 hours of VHS-C video-tape were collected, transcribed, and recorded in fieldnotes for ongoing micro-ethnographic analysis. Transcriptions included the time and date of each session, contextual variables, verbatim recordings of verbal interactions, and

descriptions of non-verbal behaviors. The dates and nature of video-recordings are included in Appendix B.

### Ethnographic Interviews

In addition to video-recording and observational techniques, ethnographic interviews were conducted with residents, staff, family members, and therapists. Initial formal and informal interviews were conducted prior to implementation of the service delivery model to obtain information relating to the subject's background, medical history, and daily routine. The open-ended format of questions asked during these interviews also enabled the researcher to explore the perspectives of potential interactants, including their opinions about the subject's communicative status, interpretations of non-verbal behaviors, and expectations for recovery. All formal interviews were audio-taped, transcribed, and recorded in fieldnotes for subsequent analysis. Information obtained during informal interviews was recorded in a notebook and subsequently transcribed in fieldnotes.

Toward the end of the investigation, follow-up interviews were conducted with participants as a means of "respondent validation" of findings and hypotheses. During these interviews the informants were asked more specific questions relating to perceived changes in the subject or other participant's behavior and their perceptions of the service delivery model. Segments of final interviews were

compared to excerpts from initial interviews. The dates and participants interviewed are included in Appendix B.

### Artifactual Analysis

Spradley (1980) defines cultural artifacts as "things people make and use" (p.10). Throughout this investigation, objects and aspects of the physical environment including schedules, therapist's records, photographs, medical charts, furnishings, and personal belongings of the subject, were collected or described in fieldnotes. Artifactual analysis enabled the investigator to obtain information relating to the subject's background, preferences, and status within the nursing home community. Furthermore, examination of cultural artifacts enabled the investigator to determine how various elements of the setting influenced the subject's responses and affected the attitudes and behavior of other participants.

### Stages of Data Collection and Analysis

As previously mentioned, the almost simultaneous process of ethnographic data collection and analysis was carried out in four stages. The following techniques represent a progressive narrowing of investigative focus and analysis followed by an integration of data with various theoretical perspectives.

### Descriptive Observation/Domain Analysis

The pre-implementation phase of the investigation began with five weeks of widespread participant observation

and artifactual analysis to gain an overview of the entire long-term care facility. By obtaining descriptions of the physical surroundings of the facility the investigator was able to define the parameters of the subject's communicative environment and identify contextual variables that were subject to change during the post-implementation phase of the investigation. Observations of activities that took place in the facility facilitated integration of service delivery model into the existing environment with minimal disruption to the normal routines of the participants. Finally, observations of participants in various situational contexts enabled the investigator to gain the "native's perspective" of the nursing home culture and determine if any residents met the pre-requisites for communication facilitator.

Within the first week of data collection, the investigator initiated a concurrent process of domain analysis. Fieldnotes based on descriptive observations were examined and analyzed with an eye for patterns of behavior or categories of cultural meaning. The following major domains were identified and served to structure the course of subsequent observation and analysis:

1) activities, 2) interactions, 3) responses/reactions and 4) setting. As patterns emerged from the analysis of descriptive data, more focused observations and analysis were carried out. However, the investigator continued to

make descriptive observations throughout all stages of the investigation.

#### Focused Observations/Taxonomic Analysis

After obtaining an overview of the long-term care facility, the scope of observation was narrowed to focus on the subject's communicative environment. Specific questions were formulated relating to each domain of interest and observations were carried out to answer these questions. Representative samples of the subject and other participant's behaviors were obtained via observation and video-recording at different times of day and in various situational contexts including pre-existing speech and occupational therapy sessions, "mealtimes", and facilitator training sessions. During this stage of the investigation, the WNSSP was administered to obtain Jason's baseline responses, and formal interviews, video-recordings, and artifactual analysis were carried out.

Following facilitator training, the subject was re-evaluated with the WNSSP and five sessions of focused observation were carried out to determine if any changes had taken place in the subject or other participant's behaviors. The Investigator also conducted informal interviews with the facilitators, family members and therapists to gather their initial perspectives about the service delivery model.

The second level of data manipulation, taxonomic analysis, was initiated along with focused observations. Fieldnotes based on observational data, ethnographic interviews, artifactual analysis, and transcriptions of video recordings were examined to identify subdivisions or categories within domains. For example, within the domain of interactions, the following interactional dyads were identified: therapist/client, staff/patient, husband/wife, father/son, facilitator/subject. Structural questions were applied to these taxonomies to discover differences and similarities across and within domains. For example, how did Jason's responses differ within each interactional dyad? The process of formulating structural questions, observing, collecting, and analyzing fieldnotes continued in a cyclic fashion, further narrowing the scope of observation.

#### Selected Observation/Componential Analysis

As facilitator-based intervention was initiated, the researcher began focusing primarily on therapeutic interactions between the subject and facilitators.

Selected observations were guided by specific questions relating to the subject's responses to the facilitators and intervention techniques, the facilitator's behaviors, and observed patterns of interaction.

The third level of data manipulation, componential analysis, entailed a search for attributes or components of

meaning within categories (Spradley, 1980). Fieldnotes relating to the subject's behaviors were coded in terms of the observed response and the stimuli or interactants that elicited the response. These data were then compared and contrasted to determine how responses differed within and across situational contexts. At this time, the investigator began formulating hypotheses to explain observed behaviors and patterns of interaction. To validate the hypotheses, the investigator made further selected observations to identify repeated occurrences of specific responses within the same contexts.

#### Theme Analysis and Triangulation of Data

The overall efficacy of the service delivery model was evaluated by integrating data collected during the pre-implementation and post-implementation phases of the investigation. The investigator reviewed approximately 500 pages of fieldnotes based on observational data, video-recordings, artifactual analysis, and ethnographic interviews. "Strips" of data (Agar, 1986) were then extracted from fieldnotes and categorically stored in computer files. Video-recordings of specific interactions and events were also reviewed to assure the accuracy of initial transcriptions. Qualitative data were triangulated with quantitative measures to determine the extent and nature of changes in the subject's cognitive, communicative and motor behaviors.



The final stage of data manipulation, theme analysis, was carried out to discover the underlying mechanisms which structured the behavior of participants. While previous stages of the investigation had involved a progressive narrowing of focus, data were now examined within the broader context of the entire cultural scene. The investigator employed the process of "theoretical triangulation", approaching data from multiple perspectives and with various hypotheses in mind (Hammersley and Atkinson, 1983). A review of the literature was conducted and data were subjected to theoretical perspectives from various disciplines which might explain the findings of the investigation and the cultural behavior observed within the long-term care facility.

#### Implementation of the Service Delivery Model

Guidelines for implementation of the facilitator-based service delivery model were established at the inception of the project; however, procedures were modified based on the unique characteristics of the facility, subject, and communication facilitators. Prior to facilitator selection, the investigator met with the administrator of the facility to discuss the research project and obtain permission for the study to take place. At this time the administrator signed a consent form and received an abstract outlining the procedures to be utilized during the investigation. Jason's wife, May, and the facilitators

also signed consent forms after being informed of the nature of the project (see Appendix C).

#### Facilitator Selection

The role of the communication facilitators was to employ sensory stimulation techniques and provide the subject access to assistive technology which would enable him to effect changes in his immediate environment. Specific guidelines for facilitator selection had not been addressed in the literature. However, the following criteria were established based on the long-term nature of the study, the therapeutic techniques to be employed with the subject, and the Investigator's observations of characteristics which have been conducive to partner training with families, teachers, and staff involved in the programs of non-verbal individuals.

- a. relatively stable medical condition
- b. awareness of self and surroundings
- c. motivation to interact with peers
- d. willingness to participate in long term study
- e. adequate use of upper extremities
- f. no severe short term or long term memory deficits
- g. verbal intelligibility

The facilitators had to be physically able to participate in all phases of the investigation, remember to attend training and intervention sessions, be willing to interact with the non-verbal subject and other residents, manipulate objects used for sensory stimulation, and acquire new skills related to augmentative intervention with the subject.

Based on extensive observation within the long-term care facility, several residents appeared to meet the outlined criteria. The residents identified as potential facilitators included two young men in wheelchairs and an elderly, married couple. The staff Speech Pathologist was consulted and asked his opinion about the qualifications of these individuals. He was familiar with all of them and indicated they were appropriate candidates, meeting the outlined criteria for communication facilitator. Unfortunately, the elderly couple began experiencing medical problems shortly after the initial observation period. The two young men, Dan and Frank, agreed to participate in the investigation.

#### Facilitator Characteristics

Frank, 35, was paraplegic as the result of a construction accident six years prior to the onset of this investigation. He sustained a head and spinal cord injury, was non-responsive for six weeks, and then spent an additional six months in a large rehabilitative facility in southern Louisiana. Frank became independently wealthy following a large insurance settlement with the construction company. Consequently, he had access to many material possessions that other residents did not. His room contained a large screen television, Video Cassette Recorder (VCR), and various remote controls. Frank placed an emphasis on his grooming habits and was one of the few

residents in the facility with an extensive wardrobe. Additionally, he kept a barbecue grill in the back of the facility and owned a compact freezer stocked with meat.

Dan, 34, was an ex-musician confined to a wheel-chair after experiencing kidney failure secondary to drug abuse. He was divorced, had a ten year old daughter, and spent most weekends with his mother. Dan underwent dialysis three times a week at a local hospital and at the time of initial observation, shared a room with Frank. He was subsequently transferred to another room in the facility. Dan was often observed outdoors socializing with other residents, smoking, or playing with a remote control car.

#### Facilitator Training Sessions

Facilitator instruction was conducted by the investigator over ten one-hour sessions that included an initial interview and inservice, an introductory session, Six informational sessions, two hands-on training sessions, and a final interview and "comprehension check". The dates and nature of training sessions are contained in Table 1.

The informational content and progression of training sessions were derived from the Curriculum Guide for an Introductory Course in Augmentative Communication (ASHA, 1986) and modified based on the knowledge and skills needed to provide communicative intervention to STR brain-injured adults. The individual characteristics, background knowledge, and learning rate of the facilitators also

influenced training procedures. All training sessions were video-recorded and transcribed in fieldnotes for the subsequent analysis of specific training techniques, instructional strategies, and facilitator responses. The objectives and informational content of each session are outlined in Appendix D and detailed below.

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Table 1  
Facilitator Training Schedule

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August 17	Initial interview, inservice, demonstration adapted appliances and sensory stimulation techniques
August 31	Introduction to Jason
September 1	Microswitch technology, control interfaces
September 3	Environmental control units
September 4	Low technology communication devices
September 8	High technology communication devices
September 10	Overview sensory stimulation kit and rationale behind sensory stimulation techniques
September 15	Demonstration sensory stimulation with Jason
September 20	Hands-on augmentative techniques
September 21	Hands-on sensory stimulation
September 21	Comprehension check, final interview

---

#### Initial Interview and Inservice

A joint interview was conducted on August 17, to gauge the facilitators familiarity with Jason's background, medical condition, and functional status. Additional information was obtained relating to the facilitators' personal histories and experiences with disability. An excerpt of the initial interview is contained in Appendix E. Immediately following the interview, the investigator conducted a brief inservice which included information

about STR individuals, an overview of Jason's functional and communicative status, and the rationale and goals of the investigation (see Appendix F). A demonstration of assistive technology and sensory stimulation techniques was also provided. Following the initial interview and inservice, all training sessions were conducted in the subject's room. Therapists, family members and staff were encouraged to attend the sessions to ensure generalization of strategies to different situational contexts.

#### Introductory session

On August 31, the facilitators were formally introduced to Jason at his bedside. Following the introduction, the investigator described the investigation to Jason (see Appendix G) as May, his wife, shared photographs and information about his past history with the facilitators. Because he lacked an interpretable response mode, it was difficult to evaluate Jason's level of comprehension. Nonetheless, it was deemed essential to inform him of the project prior to the implementation of communicative intervention. Immediately following the introductory session, informal interviews were conducted with the facilitators to obtain their initial impressions of Jason's functional status.

### Assistive Technology Sessions

Assistive technology training focused on the operation and application of technology for environmental control and communicative augmentation. Information was presented along a continuum beginning with simple microswitch technology and ending with high technology communication devices. Table 2 contains a list of the equipment used during these sessions.

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Table 2  
Equipment Used During Assistive Technology Training Sessions.

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#### Switches (manufacturers)

Wafer Switch (Tash)  
Plate Switch (Don Johnston)  
Wobble Switch (Prentke Romich)  
Button Switch (Tash)  
Vibrating Switch (Steven Kanor)  
Voice Activated Switch (Steven Kanor)  
Touch Plate Switch (Steven Kanor)

#### Environmental Control Units

Environmental Control Unit (ECU) (Prentke Romich)  
Ablenet Control Unit (Ablenet)  
Slide Projector Interface (Tash)

#### Switch Activated Appliances and Devices

modified (by investigator) tape recorder  
modified siren  
modified fan  
Vibrating Pillow (Steven Kanor)  
slide projector  
Battery Adapter

#### "Low Technology" Devices

Yes/No Indicator (Zygo)  
Dial Scan (Don Johnston)  
IntroTalker (Prentke Romich)

#### "High Technology Device"

The Liberator (Prentke Romich)

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Note. Descriptions of equipment are provided in Appendix H.

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Microswitch training began with a description and demonstration of adapted battery operated appliances and control interfaces. After discussing the rationale behind microswitch technology, the investigator provided the facilitators a handout pertaining to the progression and goals of switch training with minimally responsive adults (see Appendix I). The facilitators were encouraged to manipulate various switches and battery operated appliances.

Session three focused on equipment specifically designed for environmental control via microswitch technology. The investigator began the session with a demonstration of a slide projector adaptation from the Ablenet Corporation. A wobble switch from the Prentke Romich Corporation was mounted by Jason's head, and slides of his home, belongings, and relatives were projected on the door to his room. The investigator also demonstrated an environmental control unit (Ablenet) interfaced with a radio and a remote environmental control unit (Prentke Romich) interfaced with a television.

Sessions four and five were devoted to low and high technology devices for communicative purposes. The investigator familiarized facilitators with the unique features of several communication devices including the on-off switches, overlays, and switch interface locations.



Toward the end of each session the facilitators manipulated and programmed the devices.

### Sensory Stimulation Training Sessions

Sensory stimulation training began on September 10, with a discussion of non-responsive patients, the detrimental effects of sensory deprivation, and the benefits of multimodality sensory stimulation. During this session, the facilitators were familiarized with the contents of the "sensory stimulation kit" listed in Table 3.

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Table 3  
Contents of Sensory Stimulation Kit

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(Contained in large "Caboodle" makeup box)	
<u>Olfactory</u>	<u>Auditory</u>
Scented Candles	"christmas" bell
gardenia	mini-piano
rose	transistor radio
magnolia	AT&T Artificial Larynx
peach	wax paper
strawberry	
vanilla	<u>Visual</u>
Extracts	"christmas" snow globe
vanilla	"puppy" greeting card
rootbeer	flashlight
orange	colored paper
almond	
peppermint	<u>Tactile</u>
coffee	AT&T Artificial Larynx
chocolate	sand-paper
banana	rough cloth
rum	smooth cloth
whisky	felt
crab boil	feather
<u>Gustatory</u>	
Kitchen Helper ("gravy")	
chocolate extract	
coffee extract	

---

During session seven the Investigator demonstrated sensory stimulation techniques with the subject. The following guidelines for the presentation of stimuli were provided.

1. Begin with olfactory stimuli and then progress to tactile, visual, and auditory stimuli.
2. Present the selected stimuli.
3. Wait approximately five seconds for response.
4. If there is no response, present again and discuss stimuli
5. If there is a response, acknowledge it and present the stimuli again.
6. Present the next stimuli.

#### Hands-on training

Sessions nine and ten were devoted to hands-on training with the subject. During these sessions, the furniture arrangement in the subject's room was modified to accommodate the facilitators' wheelchairs. Chairs were moved to the sides of the room and the bed was pulled away from the wall allowing the facilitators to access Jason's bedside.

During sensory stimulation activities, each facilitator was provided access to the sensory stimulation kit, and was assisted by the investigator with stimuli selection and appropriate presentation techniques. During assistive technology sessions, the investigator positioned the subject and equipment so that the facilitators could easily access various switch sites. The facilitators provided maximum physical assistance to the subject so that he could activate various battery operated appliances.

During the final training session, the investigator established that each facilitator demonstrated the capabilities to apply microswitch technology and was able to independently employ sensory stimulation techniques. Follow-up interviews were then carried out to obtain the facilitators initial impressions of the service delivery model and the subject's behavior during facilitator training sessions.

#### Communicative Intervention

Facilitator-based intervention began on September 24, and was carried out for eight weeks (30 sessions). While initially it had been anticipated that the facilitators would provide "therapy" together, scheduling conflicts necessitated separate visits. Each facilitator was placed on a flexible time-schedule with a combined total of at least 5 half-hour sessions a week. Table 4 contains the dates, facilitator, and nature of each session. During the first two weeks of intervention (9/22-10/6), sensory stimulation and assistive technology were provided on alternate days. Each subsequent session included at least a brief period of sensory stimulation. The WNSSP was administered during the last session of each week to document changes in Jason's adaptive responses and to develop objectives for subsequent sessions.

Table 4  
Dates, Facilitator and Nature of Communicative Intervention Sessions.

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September 24	(Dan)	Sensory stimulation
September 25	(Frank)	Sensory stimulation
September 27	(Frank)	Assistive technology
October 1	(Frank)	Sensory stimulation
October 6	(Dan)	Assistive technology
October 8	(Frank)	Sensory stimulation
October 11	(Frank)	Sensory stimulation
October 14	(Frank)	Sensory stimulation
October 15	(Frank)	Assistive technology
October 19	(Frank)	Sensory stimulation
October 20	(Dan)	Assistive technology
October 22	(Frank)	Sensory stimulation
October 23	(Frank)	Assistive technology
October 29	(Dan)	Sensory stimulation
October 30	(Dan)	Sensory stimulation
October 31	(Frank)	Sensory stimulation
November 2	(Frank)	Sensory stimulation
November 3	(Frank)	Sensory stimulation
November 5	(Dan)	Assistive technology
November 6	(Frank)	Assistive technology
November 8	(Frank)	Sensory stimulation
November 9	(Frank)	Sensory stimulation
November 11	(Frank)	Sensory stimulation
November 14	(Frank)	Assistive technology
November 15	(Frank)	Assistive technology
November 16	(Frank)	Sensory stimulation
November 17	(Frank)	Sensory stimulation
November 19	(Frank)	Sensory stimulation
November 21	(Frank)	Assistive technology
December 6	(Frank)	Assistive technology

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#### Sensory Stimulation Sessions

Nineteen sensory stimulation sessions were carried out over the course of intervention. At the beginning of each session the facilitators positioned themselves at Jason's bedside and were provided access to the sensory stimulation kit. Intervention initially focused on multi-modality sensory stimulation, that included the presentation of olfactory, auditory, visual and tactile stimuli. During

the first two weeks of intervention, the information Jason's wife and son provided the facilitators about Jason's past preferences and experiences guided the selection of stimuli. For example, during olfactory stimulation activities, extracts and crab boil were presented to Jason while facilitators discussed crawfish boils, liquor, coffee and chocolate. Facilitators were encouraged to note any perceived changes in the subject's communicative behavior or specific responses to stimuli. The progression and selection of specific stimuli was modified over the course of the investigation based on the Jason's responses and the identification of preferred sensory modalities.

#### Assistive Technology Sessions

Eleven assistive technology sessions were carried out over the course of communicative intervention. During the first two microtechnology sessions (September 20 and October 5) the facilitators were provided plate switches (Don Johnston) that were interfaced with reinforcers such as music, a vibrating pillow, a fan, or siren. The investigator assisted the facilitators by mounting the switches at various activation sites on Jason's body while they manipulated the reinforcers. During the next six sessions, a hospital table containing reinforcers or low-tech communication devices was placed over Jason's bed as the facilitators independently placed switches at various

access sites. During the final two assistive technology sessions, The Liberator (Prentke Romich), a high technology communication device was configured with an eight location overlay and placed on Jason's lap allowing for incidental or intentional activation. The facilitators interacted with Jason and provided physical or verbal prompts to encourage incidental or intentional activation.

## CHAPTER IV: RESULTS

### Overview of The Setting

The research site selected for this investigation was a 113 bed, skilled nursing facility located in Baton Rouge, Louisiana. It was one of the few nursing homes in the area providing long-term care to medically unstable individuals who required ongoing skilled nursing and specialized medical equipment. In addition to acute-care cases, the nursing home accommodated elderly, mentally ill, and young individuals (9-48 yrs), who were no longer able to care for themselves. A key to the abbreviations used to denote the names of the individuals who participated in this study is contained in Table 5. As previously mentioned, all names are pseudonyms to protect the confidentiality of the participants.

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Table 5  
Key to Abbreviations used to Denote Participants

J=	Jason, Subject
M=	May, Subject's wife
S=	Son, Subject's son
SLP=	Speech Language Pathologist, Ben
I=	Investigator
AD=	Activity Director
F=	Frank, Facilitator
D=	Dan, Facilitator
N=	Nurse
NA=	Nurses' Aide
R=	Ray, Subject's brother
FW=	Frank's Wife, Subject's sister-in-law
Obv=	Observation
K=	Ken, subject's grandson

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### Background Information

The staff speech-language pathologist (SLP) provided the following information about the long-term care facility during an interview on July 30, 1992. Prior to December, 1991, rehabilitative services were contracted through various home health organizations. The administrator subsequently integrated a part-time, in-house rehabilitative staff which included the SLP, an occupational therapist (OT), physical therapist (PT) and rehabilitative assistant. Residents were provided rehabilitative services based on physician referral and adequate insurance coverage. The SLP, however, was willing to render services to "charity cases", like Jason, who could not afford, but were in need of therapy.

### Physical Surroundings

The nursing home was divided into two main sections, each equipped with a nurses' station and dining room. Jason's room, along with those of the majority of medically unstable residents, was located in Section 1, where back-up generators assured continuous function of life support systems. As indicated by the following excerpt taken directly from fieldnotes, the physical characteristics of Section 1 were comparable to that of a hospital.

The nurse's station, with uniformed staff, patient charts and medicine carts, is directly across from the main entrance to Section 1. The atmosphere in this part of the facility is sterile and quiet except for the intermittent sounds of screaming and moaning. The hallways



are devoid of wandering residents and empty except for the occasional presence of nurses, aides and custodians. (Fieldnotes, July 8)

The nurses' station, parallel to the main entrance of the facility, consisted of a large, circular desk, 2 walls of medical charts, and an adjacent medical supply room. Blue medicine dispensement carts were located across the hall from the desk, next to the dining area. The structural characteristics of this area, along with the uniformed staff members, medical paraphernalia, bright florescent lighting, and smell of disinfectant, reinforced the "hospital-like" image of Section 1.

The dining area, across from the nurses' station, was a large, glass-enclosed room, described by the investigator as smelling of "old food". The room was heavily populated during mealtime and tri-weekly "bingo" games, but remained empty most of the day. Behind the dining area, was a tiny but highly frequented area, "the drink and snack room". It was later discovered that change for the vending machines was a valuable commodity among both staff members and residents.

Adjacent to the dining area, there was a small lobby or waiting area. The room had shiny white floors and housed uncomfortable furniture, spaced widely apart. Few residents were observed in the lobby area; instead, they congregated outside the glass doors at the entrance of Section 1.

The administrator's office was adjacent to the nurses' station. During an initial meeting, the investigator noted that the room looked like a page out of Better Homes and Gardens. The soft lighting, Victorian style furniture, plush carpeting, abundance of plants, framed prints, and fragrance from three air fresheners were in stark contrast to the physical environment outside the perpetually closed office door. In a later interview, the investigator mentioned this disparity to Jason's wife, who responded: "That lady don't care about the residents. All she cares about is making her office look nice." (Interview, September 26)

## Section 2

As indicated in the following excerpt from fieldnotes, Section 2 of the facility differed from Section 1 in terms of the atmosphere and amount of activity which took place during the day.

This part of the facility houses many of the healthy residents who interact with staff and visitors. The T.V. room, across from the nurses' station, is filled to capacity with young and old residents. The T.V. room is the most comfortable location in the nursing home, with worn, overstuffed couches, chairs, and home-like furnishings. The therapists, along with the nursing director, dietician, and activity director, have offices in the back. (July 8, 1992)

Section 2 was heavily populated with staff members and residents, wandering or wheeling themselves through the halls. The atmosphere appeared more relaxed than that in

Section 1, with loud talking between staff and residents and the smell of smoke rather than disinfectant. The television room had an abundance of sofas and chairs, placed side by side, along with a piano and large screen television. Whereas Section 1 appeared to be devoted to "nursing", parts of Section 2 were reminiscent of a "home".

#### The Residents' Rooms

The basic decor of the rooms in both sections of the facility was "institutional-like" with gray, blue, pink, or mauve cinder block walls, two hospital beds, hospital trays, nightstands, and privacy curtains. Four residents shared one bathroom placed between two rooms. During a tour of the facility with the SLP, the investigator had an opportunity to visit both the medically unstable or "sick" residents and more able-bodied, "healthy" residents' rooms. In each of the eight healthy residents' rooms, the environments had been modified in some way, whether with pictures of family members, home furnishings, appliances, or plants. Some of these residents furnished their own lamps, one had an elaborate entertainment system, and many had remote controls to access their televisions. Additionally, it was noted, healthy residents were able to obtain privacy by closing the doors to their rooms. Many of the sick residents, however, existed in bare, poorly lit surroundings, with few observable personal effects and an overall inaccessibility to call buttons.

Unobtrusive observations of these rooms were possible as doors were usually left open unless therapists were present.

#### Opportunities for Interaction

The majority of observed social interaction between residents took place in the circular driveway outside the doors of Section 1, television room of Section 2, or the dining areas during meals and bingo. Sick residents were infrequently observed being placed by staff in these areas; however, those who did not own wheelchairs or geriatric (geri) chairs remained in their rooms.

During the pre-implementation phase, many same-age and mixed-age conversational dyads were observed outside, in the television room, and in the halls of Section 2. Additionally, some of the younger male residents reported visiting each others rooms. Prior to facilitator training sessions, there were no observed in-room or out-of-room social interactions between healthy and sick residents; however, Dan, one of the facilitators, later reported visiting Jason on several occasions.

#### Jason's Communicative Environment

For the purpose of this investigation, the communicative environment refers to the context in which interactions between Jason and other participants took place. Jason's communicative environment was essentially limited to his room as he did not have access to a

wheelchair. The room was located in the back of Section 1, next to the dialysis room and adjacent to the chapel. The chapel was seldom occupied and the dialysis room frequented only by staff and sick residents. During the pre-implementation phase, few healthy residents were observed venturing into this area of the facility.

Like most residents, Jason's name was placed on the outside of the door to his room; however, it was misspelled. An identification card, inside the closet door, provided general information regarding Jason's medical status and the medication he was receiving (tracheostomy, gastrostomy, seizures, phenobarbital), along with an overall medical diagnosis of "semi-comatose".

The interior of the room was identical to other residents' in terms of the furnishings and basic physical arrangement (see Figure 3). However, unlike many residents, there was an overwhelming presence of medical paraphernalia and a sign above the bed which read:

NOTICE: PATIENT MUST BE TURNED EVERY TWO (2) HOURS

The following excerpt from fieldnotes describes the institutional-like setting in which Jason was observed during the pre-implementation phase.

The walls are gray cinder-block, there are two hospital beds, two hospital trays, water pitchers, nightstands, polished white floors, a privacy curtain and bathroom... Jason's bed is located between a suction machine, I.V. stand, and oxygen machine. An emergency call button and colostomy bag hang at the side of the bed. The OT has posted "turn" and

"splint" schedules on the wall behind the bed.  
(Fieldnotes, July 8)

The preponderance of medical paraphernalia was needed to suction and moisten Jason's tracheostomy, provide a continuous flow of fluids and nutrition, and collect urine and waste. The mechanized bed frame allowed Jason to be placed in a variety of positions and the schedules on the wall were designed to insure that Jason was turned with sufficient frequency to prevent bed sores and further contractures.

#### Atmosphere and Decor

The atmosphere in the room was described in fieldnotes as "gloomy", with gray walls, lack of appropriate lighting, and a perpetually drawn window shade. There were no discernable outside environmental sounds because Jason's room faced a wall toward the back of the facility. There was, however, the intrusion of aversive noises from inside the facility such as incessant screaming from across the hall and a noisy oxygenator.

In terms of decor, the medical paraphernalia and hospital furnishings contrasted with a poster of G-stringed women on motorcycles, a picture of a gypsy, and a painting of Jesus hung side by side on the wall across from Jason's bed. The only other observable personal belongings in the room were a television, a radio, and a photograph of Jason's niece placed behind the headrail of his bed.

Three of the potential facilitators were confined to wheelchairs; thus it was necessary to determine if the room was large enough to allow them access to Jason's bedside. The room was small and crowded with medical equipment and furniture; however, Jason's wife explained that the hospital bed could be pulled away from the wall, siderails pulled down, and chairs moved to the sides of the room if more space was needed. Additionally, it was noted that electrical outlets were available for use of environmental control units.

### The Participants

#### The Residents

Weather permitting, a variety of residents could be found in the circular driveway outside the doors of Section 1. Some residents were "wanderers", walking up and down the driveway, but never leaving the boundaries of the facility. Others were "beggars", asking visitors for change or cigarettes. A large, friendly woman would open the door for visitors, in the hopes of receiving a "tip". The "crazies", as Jason's wife referred to them, would verbally or physically harass residents and visitors or eat cigarette butts found lying on the ground. Two young male paraplegics and one quadriplegic resident could consistently be found socializing or napping outside in their wheelchairs.

The dining areas were observed during meals, bingo, craft activities, and birthday parties. Meals were served from 7:30am-9:00am, 11:30am-12:45pm, and 4:30pm-6:00 pm. Residents physically unable to access the dining areas were served trays in their rooms. However, one of the orderlies asserted that when he was on duty he took all of his residents to the dining room, regardless of "how bad off they are". Some of the elderly residents observed in the dining area were in poor health or uncommunicative, however, others appeared healthy and were eager to engage in conversation. A non-verbal woman with an elaborate gestural system acted as a "helper", serving meals and clearing tables. She visited Jason's wife and son twice a day, delivering 3 cups of cold coffee in exchange for aluminum cans.

Residents observed in the television room of Section 2 included two young individuals with severe cerebral palsy, a man who talked to himself and threatened visitors with eternal damnation, several elderly residents and a young man in a wheelchair who sat smoking cigarettes and eating ice out of a large cup in his lap. This man (Dan) was identified by the investigator as a potential facilitator.

In addition to the residents observed in the above social situations, there were the aforementioned, sick residents, confined to their rooms and isolated from others



in the facility. Aside from their medical problems, some of the sick residents exhibited profound physical disabilities, cognitive deficits, or suffered from progressive debilitating diseases. The investigator was intrigued by two of these room-bound residents. One, Mr. H. suffered from Alzheimer's disease and on most occasions sat tied to a chair in his bare room, attempting to escape his binds. The other resident, Annie, was nine years old and experienced medical complications related to severe cerebral palsy. Her presence within the facility illustrated the diversity of the population and conflicted with the perception of nursing homes as existing for the elderly.

#### The Administrator

Based on initial contact and observation of the administrator, it was determined that she would serve primarily as a "gatekeeper", providing access to the nursing home and granting permission for the study to take place. It had been anticipated that as Administrator she could provide valuable information about the subject and potential facilitators. However, it was later discovered, through interview and observation, that she spent little time at the facility, was inaccessible when present, had minimal contact with the residents, and was unfamiliar with Jason's case. Jason's wife reported:

M: She came in one day and thought he'd had a stroke, and asked me questions. I thought,

you're the administrator, you should know.  
(Interview, August 12)

#### Additional Personnel

During an interview on August 12, Jason's wife explained that the administrative secretary, social worker, activity director, and dietician had minimal direct contact with Jason. The secretary acted as an intermediary between the administrator and residents. She did not interact with Jason, but socialized with his wife and son. The social worker was responsible for procuring Jason's wheelchair. However, at the time of the investigation, little progress had been made in this matter. The dietician had no association with Jason because he had a tracheostomy and dietary needs were met through a gastro-intestinal (GI) tube. The activity director had evaluated Jason's case when he entered the facility and determined he was too low-functioning to engage in recreational activities.

#### The Staff

As potential interactants within Jason's communicative environment, the nurses, aides, orderlies, and custodians were considered potentially valuable informants. It should be noted that a high rate of turnover precluded extended observation and follow-up interviews with individual staff members. Moreover, initial focused observations revealed that Jason's wife and son performed many of the assigned duties of staff members such as turning Jason to prevent bed-sores, emptying his colostomy bag, suctioning his

tracheostomy, adjusting his catheter, and injecting water into his GI tube. When asked why they assumed these duties, Jason's wife responded:

M: I had my fight with them. I came in and Jason was wet from here to his feet even this here (points to suction machine) he'd coughed and the machine was clogged up. His catheter had come loose and he had waste on him from here to his feet. Mucous was here on this cotton covering the trach and he wasn't getting any oxygen. (Interview, September 26)

Nonetheless, most of the staff members assigned to Section 1 came in contact with Jason on a daily basis. Nurses administered medication three times a day, checked Jason's blood pressure and provided nutritional supplements through the GI tube. Nurse's aides infrequently checked his colostomy bag and added fresh water to the suction machine. Custodians cleaned the bathroom and mopped the floor in Jason's room, and orderlies changed Jason's bedding and physically carried him to the facility whirlpool two to three times a week.

#### The Rehabilitative Staff

At the time of initial observation, Jason was provided a daily 20-minute co-treatment of speech-language and occupational therapy. Although a PT was on staff, Jason was not provided physical therapy during the pre-implementation phase.

The SLP obtained his Master's Degree at a large university in Southeastern Louisiana and started working at the facility in December of 1991. His primary therapeutic

interests were traumatic brain injury (TBI) and aphasia. After attending a seminar on coma stimulation he decided to provide therapy to Jason, although insurance would not cover the cost.

SLP: If it hadn't been for me having a little seminar on coma stimulation I wouldn't have worked to pick him up. (Interview, July 30)

The OT obtained his degree at a University in Southern Louisiana and also began working at the facility in December of 1991. He was initially reluctant to provide Jason services; however, the SLP reportedly convinced him that therapy would be beneficial.

SLP: The OT and PT they were reluctant to pick him up but this was something I had force the issue. (Interview, July 30)

Along with the SLP and OT, a rehabilitative assistant was present at each therapy session. Her duties included obtaining doctors signatures on forms and physically assisting the therapists. She was a college student who had received no formal rehabilitative training.

### The Family

Jason's wife, May, and 26 year old son, Jason Jr., arrived at the facility each morning at 6:00 and remained until 3:00pm. During initial observational sessions they could be found outside smoking, tending to Jason, or sitting silently by his bedside reading and re-reading novels. Both interacted frequently with staff members, therapists, and residents.

In terms of other family members, May reported that Jason's mother refused to visit the nursing home until he was "out of the coma". Jason's youngest son was in the Army, and his two daughters visited infrequently. May reported that although Jason came from a large family and had many friends, he rarely received visitors.

#### The Roommate

Jason shared his room with a non-verbal elderly man who had suffered a right hemisphere stroke. When asked about Jason's placement with another brain-injured individual, the SLP reported that residents were often grouped together based on characteristics or disorders. Consequently, the non-verbal residents were housed together while the "screamers" (residents who made a lot of noise), were placed toward the back of the facility. Jason's wife added that the administrator refused to place anyone in Jason's room unless they had similar characteristics.

M: She wouldn't put anyone in this room unless he was just like Jason, the same kind of condition Jason he was in. They put the same kinds together. (Interview, July 9)

#### The Subject

The following excerpt taken directly from fieldnotes relates to the investigator's initial impression of Jason.

Jason lays silently in a hospital bed wearing a hospital gown and staring straight ahead at the wall. He does not acknowledge my presence...He is pale, has a tracheostomy, gastro-intestinal (GI) tube, and a full colostomy bag hangs from his bed. His hair is greasy, face is mask-like, hands are clenched and body is drawn up with contractures. His arms are covered with tatoos (drawing of a heart with the inscription "J.C. + M.C."). Pillows are placed under his knees and on the sides of the bed. He frequently twitches. (Fieldnotes, July 8)

Based on Jason's appearance, apparent medical problems, physical condition, and behavior he was described in fieldnotes as "sick-looking" and "non-responsive". Jason was unable to provide a verbal interview; thus, background information was obtained via ethnographic interviews with family members and the SLP.

Jason suffered a heart attack on June 22, 1991, following a series of adverse incidents. His wife reported:

M: He was depressed, you could see it in his face, he was depressed. He'd lost his job, couldn't find no work, was junking his car to make money. He was really depressed. (Interview, August 12)

While initially pronounced clinically dead, Jason was revived. Unfortunately, prolonged anoxia (loss of oxygen to the brain) resulted in global neurological damage. Jason spent two months in an Intensive Care Unit (ICU) and was subsequently transferred to the skilled nursing long-term care facility. May reported that physicians and social workers did not offer her the option of caring for Jason at home.

M: They wouldn't let me take him home. They said if he was to go home, he woulda died. I wasn't equipped to take care of him, they said. To go home would have been writing his death sentence. (Interview, September 26)

Once admitted to the facility, neurologists placed conflicting diagnoses in Jason's chart, labeling him as both comatose and existing in a PVS. When asked why Jason had not been referred by physicians for rehabilitative services, the SLP indicated that this was due to poor prognosis for recovery of function.

SLP: Okay, well the doctors were unaware that therapy was being offered uh, they just weren't educated to the fact that therapy could be offered to someone in a coma or vegetative state. Those were the initial diagnoses, you see here in the nursing home the diagnosis that's put on the charts is the one that stays. (Interview, July 30)

Jason's wife noted that the same neurologists gave family members little hope for Jason's recovery.

M: They (the neurologists) said he'd never do nothing that he'd stay in a vegetative stage for 20-25 years. (Interview, September 26)

The diagnoses of doctors were reflected in participant descriptions of Jason's condition and behavior. His wife referred to his condition as both comatose and "a vegetative stage". Other terms used by participants to describe Jason's condition during the pre-implementation phase included: "semi-comatose", "a vegetable" and "comatose-like".

### Activities

The activity director reported that she posted a calendar of events in each resident's room at the beginning of each month. Upon observation, however, it was revealed that many of the "sick" residents were not provided schedules or included in these activities. Furthermore, examination of three previous schedules revealed that while the dates on top of the calendars changed, activities and social events remained essentially the same each month.

The activities provided for residents included games, arts and crafts, "fitness programs", monthly birthday parties, and holiday social gatherings. There was also transportation to shopping malls, libraries, and churches. In addition to structured activities, residents were observed singing in the chapel on one occasion, visiting with family members, watching television, and wandering the grounds. Some of the younger wheelchair bound residents ventured out to nearby bars, restaurants, and stores. Despite the apparent variety of daily activities, however, three of the younger residents expressed boredom and many residents appeared to spend a great deal of time sleeping in their rooms.

### Jason's Activities

May provided the following summary of Jason's daily routine. He awoke between 6:00 and 10:00 in the morning and was dressed in a fresh hospital gown by his wife or the



orderlies. Nurses administered medication at 9:00 A.M. and approximately every three hours thereafter. Rather than being served three meals in the dining room, liquid supplement was injected into Jason's GI tube throughout the day. Additional observations revealed that family members placed objects in Jason's mouth (lollipops, lemon swabs, beef jerky) throughout the day; however, he could only suck on them because a staff member "misplaced" his dentures during his first week at the facility.

Jason did not own a wheelchair or geriatric chair; thus, he spent most the time in bed with infrequent outings to the facility whirlpool. Jason Jr. reported that a wheelchair had been borrowed three months ago so that Jason could sit outside of the facility. However, subsequent attempts at obtaining geriatric or wheelchairs had been thwarted by the administrator who disapproved of the practice.

S: The administrator said if he needs a chair he should have one, he's not supposed to borrow it from another patient. (Interview, July 9)

There was a television and radio in Jason's room; however, the television was placed in a far right corner, out of his visual field and the radio was seldom turned on.

Some of Jason's "activities" were dictated by notices placed by the OT on the wall behind his bed. These schedules advised family and staff members to turn Jason onto his side and put his splints on at various times of

the day. The SLP and OT arrived weekdays at 1:00 pm and stayed until approximately 1:20 pm. Of the eighteen observed pre-implementation co-treatments, there was little variation in the nature or progression of therapeutic activities. Each session followed a fairly predictable routine in which the SLP provided gustatory input (always lemon juice), encouraged Jason to vocalize consonant-vowel (CV) combinations, helped the occupational therapist sit Jason at the side of the bed, and proceeded to ask questions, attempting to engage Jason in conversation.

In terms of resident activities, Jason's wife explained that Jason was assessed by the activity director when he entered the facility. When asked about Jason's assessment, the activity director indicated that she initially had not considered him a candidate for resident activities.

AD: When Mr. Jason first came here, really I said, well I'm not gonna do a big progress note on him because he's not going to be with us very long. Cause when this man came in here we all thought maybe he'd be here a week or two and that would be it or he would continue to be a vegetable. (November 19)

#### Pre-Implementation Phase Data

##### Subject Behaviors

Table 6 provides a summary of Jason's baseline behaviors or initial responses to sensory stimulation obtained via the WNSSP on three separate occasions during the pre-implementation phase. The highest score obtained, 22/113, indicates Jason exhibited primarily generalized or

Table 6  
Pre-Implementation Results of WNSSP.

MODALITIES	7/27	8/14	9/21
I AROUSAL/ATTENTION			
1. arousability	1	0	1
2. wakefulness	1	0	1
3. eye-Contact	1	1	1
4. attention to task	0	0	0
II AUDITORY RESPONSE			
Localization			
5. voice	0	0	1
6. sound	1	1	1
Comprehension			
7. shake hand	0	0	0
8. opn/cls mouth	2	2	2
9. stk out tongue	0	2	2
10. opn/cls eyes	2	2	2
11. raise eyebrows	0	0	0
12. move body part	0	0	0
III EXPRESSIVE COMMUNICATION			
13. vocalization	0	0	1
14. facial/gest response	0	0	0
15. yes/no	0	0	1
IV VISUAL RESPONSE			
16. hor trk: mirror	0	0	0
17. hor trk: individual	1	1	1
18. hor trk: picture	0	0	0
19. hor trk: obj	0	0	0
20. vert trk: mirror	0	0	0
21. vert trk: individual	0	0	0
22. vert trk: picture	0	0	0
23. vert trk: obj	1	1	1
24. opn/cls mouth	2	2	2
25. stk out tongue	2	0	2
26. raise eyebrows	0	0	0
27. move body part	0	0	0
V TACTILE RESPONSE			
28. touch	1	1	1
29. oral stimulation	1	1	1
30. obj. manipulation: spoon	9	9	9
31. obj. manipulation: comb	9	9	9
32. obj. manipulation: penc	9	9	9
V1 OLFACTORY RESPONSE			
33. smell	1	1	1
TOTAL SCORE	17	15	22

undifferentiated responses to various modalities of sensory input and demonstrated overall deficits in arousal, awareness, and wakefulness. The following section integrates quantitative and qualitative findings regarding Jason's overall level of awareness, behavioral responses to 5 modalities of sensory input, communicative behaviors, and motor function.

#### Arousal/Attention

Arousal or alerting refers to a continuum extending from sleep to wakefulness and includes attentiveness and vigilance. In terms of ease of arousal, at the beginning of each testing session during the pre-implementation phase, Jason required repeated presentation of at least two stimuli (touch and voice) for arousal from sleep and subsequently remained awake less than 20 minutes at a time. Once awake, his eyes remained open but primarily fixated, focusing on the investigator or other participants less than 50% of the time. Based on initial observations, Jason did not appear to focus attention, visually or auditorially, on interactions and events within his communicative environment or shift attention between ongoing events. This overall lack of responsiveness was noted by many participants including Frank who described Jason's condition during an initial interview.

F: He's in that state where he's not too responsive. He will stare when you go in the room, but that's about all. (Sept.20)

## Responses to Sensory Stimulation

### Olfactory Stimuli

During three initial administrations of the WNSSP, Jason demonstrated no observable response when presented with stimuli such as scented candles, potpourri, and cologne. He did, however, exhibit vegetative oral movements in response to food-related extracts such as peppermint, almond and banana.

### Tactile Stimuli

Jason exhibited generalized movements (postural adjustments) in response to vibratory and rough tactile stimuli applied to his extremities. He did not appear to respond to stimuli such as feathers or soft cloth rubbed on his face or extremities. Additional observations revealed that Jason did not exhibit any discernable response when staff members "cuffed" his arm to take his blood pressure, filled his GI tube, or adjusted his catheter.

### Gustatory Stimuli

It was noted during administration of the WNSSP and observation of Jason's pre-existing speech therapy sessions that sour, sweet, and salty gustatory input (lemon juice, lollipops and beef jerky) elicited continuous, non-meaningful vocalization (ah-ah-ah) and perseverative oral movements (chewing).

### Auditory Stimuli

Jason initially exhibited generalized body movements (startling) in response to sudden, loud noises such as screaming in the hall, the blaring of the loud-speaker above his bed, or his roommate's coughing. He did not, however, demonstrate localized responses to music, knocking at the door, or the sound of a ringing bell.

In terms of response to speech, Jason exhibited no response when his name was called by the investigator and did not appear to attend to conversation between other participants. Upon video-tape analysis, however, it was revealed that he demonstrated infrequent, delayed oral movement (45+ second) in response to single stage commands by the SLP such as "stick out your tongue" or "open your mouth".

### Visual Stimuli

When encouraged to visually track a flashlight, object, or individual, Jason exhibited inconsistent downward eye-movement and horizontal tracking abilities, from midline to the left with a significant response delay. He did not demonstrate vertical visual tracking or the ability to horizontally track objects from midline to the right during pre-implementation observations.

### Additional Measures

In addition to behavioral responses, the WNSSP allowed for limited quantification of the motor and communicative

behaviors manifested during sensory stimulation activities. These measures were supplemented with the staff OT's report and an augmentative/alternative communication (AAC) assessment performed by the investigator.

#### Affective Behaviors

In a resting position, Jason's facial expression was "mask-like", with muscular tension, an open mouth, and infrequent eye-movement. Affective communicative behaviors such as smiling, grinning, or frowning were not observed during the pre-implementation phase.

#### Vocalization and Verbalization

It should be noted Jason was able to achieve vocalization only when the airflow from his tracheostomy was obstructed manually or via a prosthetic device (Occluder). When occluded he produced extended vocalization following presentation of gustatory input and also inconsistently vocalized when prompted by the SLP. He was not observed, however, initiating vocalization or producing verbal approximations during the pre-implementation phase.

#### Gestural and Augmentative Communication

During an initial interview on July 30, the SLP reported that Jason used eye-blinks to indicate "Yes" (1 blink) and "no" (2 blinks). Upon observation it appeared that Jason inconsistently used a delayed, single eye-blink to indicate "yes"; however, he did not evidence a "no"

response. Aside from blinking, he was not observed using natural gestures such as nodding, shrugging his shoulders, or pointing for communicative purposes.

Attempts at implementing alternative communicative techniques such as switch operated appliances and devices, eye-gaze boards and low technology devices were not successful. This was due in part to Jason's limited voluntary motor repertoire; however, deficits in arousal and attention were equally disruptive to early attempts at augmentation. The investigator also attempted to utilize residual capabilities, (eye-blinks, vocalizations and random motor movements) to allow Jason access to augmentative techniques. For example, an auditory scan procedure was employed, which would allow Jason to "spell out" messages via eye-blinks. The investigator or family members slowly recited the alphabet and directed Jason to "blink" at a desired letter. Jason did not appear to purposefully respond during this activity. The investigator also provided Jason a voice activated switch interfaced with a vibrating pillow. Jason was able to vocalize and activate the pillow when the investigator occluded his tracheostomy tube and provided gustatory input. He did not, however, spontaneously vocalize to activate the device.



### Motor Function

The OT provided the investigator a verbal description of Jason's motor status on July 27. He reported that Jason exhibited severe joint contractures and demonstrated minimal voluntary movement or control of his head, upper, and lower extremities. He was unable to independently support his head or upper torso when placed in an upright position, exhibited overall hypertonicity of the musculature, and demonstrated frequent (1 per 10 min) clonic muscle spasms. The OT or family members splinted Jason's legs, arms, and hands to prevent further contractures. Additionally, the OT placed him in an upright position 3-5 times a week to provide vestibular and proprioceptive input.

### Facilitator Behaviors and Interactions

#### Dan

During a pre-implementation phase interview, Dan reported that he visited Jason's room on a monthly basis, held relatively high expectations for his recovery, and frequently interacted with May and Jason Jr. Observations carried out during facilitator training sessions revealed that he consistently arrived at Jason's room on time, wheeled himself to Jason's bed, leaned forward and attempted to establish eye-contact. He appeared to get as close as physically possible, looking away only when Jason's tracheostomy was being suctioned. He also remained

in Jason's room at least fifteen minutes after each session to interact with the investigator and family members.

In terms of interactive behaviors, Dan appeared comfortable conversing with Jason from the onset of the investigation. The following excerpt taken from a video-recording of a sensory stimulation training session is representative of the majority of pre-implementation interactions between Jason and Dan.

- D: (holds up banana extract) "Can you say it?"  
 J: no response  
 D: "Look this way Jason."  
 J: eyes fixated away from Dan, toward right side of bed  
 D: "Nah, I'd rather look at my wife." (holds up chocolate extract, says to Jason) "I used to take chocolate and put it on toast bread." (Sept. 21)

### Frank

During an initial interview (July 20), Frank reported that he had not "seen" Jason since he was admitted to the facility. He also expressed the belief that Jason was still "comatose". The investigator had difficulty locating Frank at the beginning of each facilitator training session and on two occasions he had left the facility altogether. Frank reported that he had been more reliable and responsible before his head injury when he "ran a crew" and "had lots of stuff to remember".

During training sessions, Frank consistently situated himself in the doorway of Jason's room, turning his chair away from Jason's bed. He rarely looked at Jason or attempted to establish eye-contact. Frank's proxemics

during initial training sessions led to the following personal note (PN) taken directly from fieldnotes.

PN: Frank sits so far away from Jason I'm beginning to wonder how he'll actually provide intervention. (Sept. 22)

Although Frank was frequently observed visiting other resident's rooms and socializing with staff members, he was reticent and appeared uncomfortable in Jason's communicative environment. During training sessions he ignored Jason and primarily conversed with other participants. An excerpt from a video-tape analysis of a September 10 training session illustrates Frank's behavior when the investigator and Jason's wife left him alone with Jason:

While we were gone, Frank, his chair turned away from Jason, was silent. He looked all around the room, finally just looking at his lap. Jason stared at the wall. (Fieldnotes, September 10)

During hands-on training sessions, Frank moved his wheelchair closer to the bed; however, he continued to turn the chair away from Jason and interact with other participants. While Frank paid little attention to Jason during the period of facilitator training, he did begin to be introspective about his own brain injury and rehabilitative history.

F: I don't know what kind of state of mind I was in when I was in a coma. I'll have to find out what kind of state of mind I was in when I was in the hospital. I'll have to find out from my family. (September 21)

### Responses to Training Techniques

The facilitators' responses during sensory stimulation training sessions were minimal. They did not ask questions and primarily responded with nods and affirmations of comprehension. Both men, however, were more responsive during sessions devoted to assistive technology and adaptive equipment. Dan demonstrated a keen interest in technology, asking for detailed descriptions and demonstrations of each device. Frank had utilized assistive technology while he was in a rehabilitation hospital and also reported previously watching a demonstration of augmentative communication devices on television.

### Facilitator Perspectives

Prior to implementation of communicative intervention, a second interview was conducted with the facilitators at which time they were asked their opinions about Jason's condition and their perspectives regarding the service delivery model. Dan indicated that Jason was responding inconsistently and that he expected positive results following implementation of the model.

D: I think right now he's kinda going through different spells. The procedures you use, I think if you continue using them that will help. Somebody who's working with him will be able to see changes, sure.  
(September 20)

Frank, on the other hand, expressed doubt as to the chances of Jason "learning" or improving, giving the

following response when asked if he'd seen any changes since Jason entered the facility:

F: No, I haven't seen any improvement. He's the same. Honest opinion, he's not far enough along. In other words he's not far enough along to learn anything. (September 20)

Frank did, however, respond positively to the sensory stimulation and augmentative techniques introduced during training sessions, stating:

F: I know these things work and I'll be willing to do anything. As far as him being in the mind of learning, no. But stuff to bring him out of the coma, yeah. He's not in a coma as far as being asleep, but he is like comatose. (September, 20)

#### The SLP

During an informal interview, the SLP reported that his therapeutic goals for Jason included increased speech production, oral-motor function and increasing Jason's ability to respond appropriately to conversation and questions. The following excerpt from a July 9 therapy session illustrates a speech production activity.

SLP: "Let me hear you say la-la-la, la-la-la."

J: (30 sec. delay) moves mouth

SLP: "There you go, try it, say la-la-la."

Another excerpt taken from a July 13 therapy session is representative of observed "questioning" activities.

SLP: "I'm gonna ask you some questions. Look here. Look at me. As loud as you can say aah, say aah. Do it, aah."

J: moves mouth

SLP: "There you go, that's close. Now see if you can say it louder. Say aah."

J: no response

SLP: "Try it again, say aah. You want some lemon juice Jason?"

J: no response, stares  
SLP: "You want to wait till you're totally able to talk. You want to wait till you're 100%? Stick your tongue out Jason."

The nature of therapeutic activities were reflected in the speech-pathologist's objective sheets from January 1992 through July 1992. During each month there was one goal relating to increased speech production, another to increased oral-motor function, and two to increased communicative function. Communicative goals primarily targeted increased affective behaviors and appropriate non-verbal responses to verbal themes. The following objectives taken from the "Updated Progress For Outpatient Rehabilitation" of June 26, 1992, are representative of "speech" and "communication" goals.

Pt. will increase ability to correctly place tongue/lips for target consonants /l,t,d,p,b,m/ by 15% with manual/tactile/visual cues.

Pt. will increase ability to exhibit appropriate reactions to verbal themes by 15%.

#### Social Interactions

In addition to providing therapy, the SLP visited Jason's room to observe training sessions and socialize with Jason and the investigator. For the most part, the SLP appeared relaxed and comfortable with Jason, playfully hitting him or "messaging" with his hair. It was noted, however, that the SLP took a disproportionate number of conversational turns, produced extended utterances, demonstrated minimal pause time, and often asked open-ended

questions Jason was incapable of answering. This rapid-fire style of interaction is illustrated in the following fieldnotes from a September 15 training session.

- SLP: "You like the Beatles? What's your favorite song from the Beach Boys, Are the Beatles better than the Beach Boys?"
- J: no response, stares straight ahead
- SLP: "Jason, I'm leaving. Gonna tell me bye? (0.5) Alright Jason, you still haven't said Ben, You want to? No? Say Pokie then, Say May, That's the one you have to say first so she'll get you things.(0.5) Say May, Say it. (0.5) I'm gonna go now. Tell me bye. See you later. Shake my hand. See you later. See you tomorrow. You have any questions? (0.5) Okay, see you later."
- J: stares straight ahead, no response to any of this (September 15)

#### The SLP's Perspective

The SLP was asked his opinion about Jason's prognosis for recovery following implementation of the service delivery model. He responded positively although he was uncertain as to how long it would take to see improvement:

- SLP: I think he's gonna improve, It's hard to put a time line on it I think that if you install a system and get a little repertoire going and it gets to be second nature and he can get to the point where he gets a reward from it I think we'll see some improvement. (September 15)

#### The Family

##### May

Jason's wife tended to initiate interaction with Jason frequently, but seldom sustained interaction for more than two conversational turns. Interactions, such as the following, were generally characterized by the narration of ongoing events, inquiries about Jason's mood and medical

condition, and discussing him with others in the third person.

M: "Ya hear the thunder outside? That's thunder.  
 J: no response  
 M: (to investigator) "He stayed up late last night.  
 M: What's the matter babe?"  
 J: no response  
 M: "What's the matter babe?"  
 J: no response  
 M: "Ya gonna talk to me or what?"  
 J: no response (July 22)

May also frequently commented on Jason's physical appearance and medical condition to staff members, therapists and communication facilitators.

M: His culture came back normal, he's just got a cold. (to SLP during July 9 therapy session)  
 M: I don't know whether to get him lotion or baby oil for his dry skin. (to Dan during September 10 training session)  
 M: I just want you to know, he used the bathroom (to OT during September 15 therapy session)

It was also noted that May interpreted many of Jason's non-verbal behaviors as signals that something was wrong; However, as indicated by the following excerpts, she did not attempt to remedy the situations.

J: coughs  
 M: "What's a matter babe?"  
 J: eyes water  
 M: "Well, I'm gonna go smoke a cigarette."  
 (August 21)  
 J: Moans  
 M: "What's wrong, huh?"  
 J: Coughs  
 M: "Is that trach bothering you?"  
 J: Coughs again  
 M: (To Frank) "You know they lost his canula."  
 (September 14)



### May's Perspective

When asked her expectations regarding Jason's rehabilitative potential May expressed uncertainty based on his diagnosis as comatose.

M: I don't understand nothing bout the coma part, lack of oxygen and stuff. Ben (SLP) says it's worse than having a bump on the head, cause the damage is done from the inside. So I don't know what can be restored and what can't. I can't ask when he'll come out cause nobody knows. (September 15)

### The Son

Jason Jr. tended to converse naturally with Jason, addressing him as "buddy" or "man", and attempting to discuss past interests. During an initial interview he reported that they were more like "best friends" than father and son. When interacting with his father, Jason Jr. tended to employ therapeutic strategies similar to those of the SLP.

S: "Go la-la-la clear your throat"  
 J: no response, stares straight ahead  
 S: "I know what you're thinking dad. Are you the only sane person left in this world? Say la-la-la."  
 J: Coughs, eyes water  
 S: "Mad? Not mad? Ya gonna say la-la-la?"  
 J: No response (August 31)

### The Son's Perspective

When asked if he felt uncomfortable interacting with his father based on his level of non-responsiveness, Jason Jr. indicated that the most significant barrier to interaction was generating new topics of conversation.

S: After a while it gets hard trying to hold a conversation, I don't have much to talk about especially since I spend all my time up here anyways. (September 20)

He also stated that the service delivery model would be beneficial if it "got someone to pay attention" to his father.

### The Staff

Various staff members were observed entering Jason's room throughout the day; however, there were few documented attempts at social interaction. The majority of staff members entered the room, tended to Jason's needs and left without saying a word. During the observational periods of August and September, only one out of the sixteen staff members administering medication or "feeding" Jason directly addressed him.

Observation: Nurse enters room, pulls up Jason's gown, begins filling G.I. tube then looks up at Jason.

N: "Hey Mr. Clark."

J: No response

N: (Finishes and leaves) (September 21)

Rather than directing conversation toward Jason, staff members tended to stand around his bed and "gossip" with May and Jason Jr. There were, however, several instances during the pre-implementation phase when staff members entered the room and observed training sessions which focused on augmentative techniques such as the slide projector or message tapes.

obs: Frank and Dan training with slides, I. demonstrates switch activation, slide of guitar is

presented. Nurses aide enters, changes supplement bag and looks up at wall.

NA: "He used to like guitars? Play guitars?"

M: (nods)

NA: (watches rest of slides)(September 1)

### The Investigator

As participant observer, the investigator's interactions became part of the data. The following excerpt taken directly from fieldnotes is representative of the investigator's initial private interactions with Jason.

(Intercom) "Miss Clark, come to the pay phone baby". May leaves and Jason stares straight ahead. I know nothing about him and feel embarrassed because I have nothing to say. I look around the room, examining artifacts. May returns and I have not said a word to Jason. (September 15)

The investigator noted that she felt more comfortable interacting with Jason during facilitator training sessions or at other times when participants were present.

### The Roommate

Mr. F. did not interact with Jason and was often overlooked by visitors as he lay in bed with the covers pulled over his head. The following interaction between Frank and Jason's wife illustrates Mr. F's invisibility.

M: "Jason might be catching a cold. Mr. F's got a cold." (points to next bed)

F: (looks surprised) "There's someone over there?"

M: "Yeah, Mr. F."

F: "I didn't know there was anybody there."  
(August 31)

### Post-Implementation Data

#### Subject Behaviors

The results from repeated administration of the WNSSP following implementation of communicative intervention are contained in Table 7. The total score of 59 obtained during final administration of the WNSSP indicates that Jason was exhibiting localized, differentiated responses to all modalities of sensory stimuli. Additionally, he demonstrated an overall increase in responsiveness to environmental events.

#### Arousal/Attention

During the second week of communicative intervention Jason began exhibiting increased responsiveness in terms of ease of arousal from sleep, longer durations of wakefulness and increased eye-contact with interactants. These behaviors were documented in video-recordings and noted by facilitator, family members, therapists and staff members who described Jason as "awake", "alert", "aware", and "attentive". Following a sensory stimulation session during which Jason visually attended and remained awake, Frank noted:

F: I see an awareness now. I never used to see any awareness but he jumped all over me today. (October 8)

The activity director reported that the overall increase in Jason's level of responsiveness altered her perception that he was comatose.

Table 7  
Post-Implementation Results of the WNSSP

MODALITIES	10/1	10/8	10/14	10/22	10/30	11/6	11/14	11/19	11/27
I AROUSAL/ATTENTION									
1. arousability	2	2	2	3	3	3	3	3	3
2. wakefulness	1	2	2	2	2	2	2	2	2
3. eye-contact	2	2	2	2	2	2	2	2	2
4. attention to task	0	1	1	1	1	1	1	1	1
II AUDITORY RESPONSE									
Localization									
5. voice	2	2	2	2	2	2	2	2	2
6. sound	1	2	2	2	2	2	2	2	2
Comprehension									
7. shake hand	0	0	0	0	0	0	0	0	0
8. opn/cls mouth	2	0	2	2	2	2	4	2	4
9. stk out tongue	2	0	2	2	4	4	2	4	2
10. opn/cls eyes	2	2	4	4	4	4	4	4	4
11. raise eyebrows	0	0	0	0	0	0	0	0	0
12. move body part	0	2	2	2	2	2	2	3	3
III EXPRESSIVE COMM.									
13. vocalization	1	3	1	1	3	3	3	3	3
14. facial/gest response	0	1	2	2	2	2	2	2	2
15. yes/no	1	1	1	1	1	1	1	1	1
IV VISUAL RESPONSE									
16. hor trk: mirror	1	1	2	2	3	3	3	3	3
17. hor trk: individual	1	2	2	2	3	3	3	3	3
18. hor trk: picture	1	2	2	2	3	3	3	3	3
19. hor trk: obj	1	2	2	2	3	3	3	3	3
20. vert trk: mirror	0	1	1	1	1	1	1	1	1
21. vert trk: individual	0	1	1	1	1	1	1	1	1
22. vert trk: picture	0	1	1	1	1	2	2	2	2
23. vert trk: obj	1	1	1	1	1	2	2	2	2
24. opn/cls mouth	2	0	0	2	2	0	2	2	2
25. stk out tongue	2	2	2	2	2	0	2	2	2
26. raise eyebrows	0	0	0	0	0	0	0	0	0
27. move body part	0	0	0	1	1	0	0	0	0
V TACTILE RESPONSE									
28. touch	1	2	2	2	2	2	2	2	2
29. oral stimulation	1	1	1	2	2	2	2	2	2
30. obj. manipulation: spoon	9	9	9	9	9	9	9	9	9
31. obj. manipulation: comb	9	9	9	9	9	9	9	9	9
32. obj. manipulation: pencil	9	9	9	9	9	9	9	9	9
VI OLFACTORY RESPONSE									
33. smell	1	2	2	2	2	2	2	2	2
TOTAL SCORE	28	38	44	49	57	54	58	59	59

AD: It's alertness, ya know like when you go in the room it's kind of a change. Like before when you went in the room he was kinda like comatose. Now it's kinda like, hmmm he knows I'm here. (November 19)

### Response to Sensory Stimulation

#### Olfactory Stimuli

On October 8, Jason demonstrated differentiated responses to specific odors. He began by turning his head and vocalizing when exposed to almond extract and subsequently verbalized "nana" in response to banana extract. Complex responses, such as simultaneously turning his head, raising his eyebrows, and vocalizing were observed when Jason was presented with the following stimuli: coffee, beer, rum, crab boil, and gravy.

#### Tactile Stimuli

On October 8, Jason withdrew his hand when it was rubbed with sandpaper. He subsequently began turning his head toward a feather and raising his arm or pulling it away when it came in contact with a vibrator. Additionally, Jason produced vocalizations which varied in length, prosody, and intensity when presented with specific tactile stimuli. He moaned loudly when tickled with a feather and produced an extended string of vocalizations when a vibrator was placed on his arm.

#### Gustatory Stimuli

During the last three weeks of intervention the facilitators began placing cotton swabs containing small amounts of coffee, vanilla, beer, or peppermint on Jason's

gums. It was during these activities that Frank and the speech pathologist noticed Jason was not exhibiting vegetative oral movements.

Obs. Frank places vanilla swab in Jason's mouth.  
 J: shifts eyes to Frank.  
 F: "Hmmm, he doesn't have that reaction with his mouth like he used to."  
 SLP: "I like how he's controlling that reflex."  
 (November 14)

#### Auditory Stimuli

During the second week of the post-implementation phase, Jason began exhibiting localized responses such as shifting his eyes and turning his head toward or away from sound sources. Jason's initial adaptive responses to auditory stimuli were noted by Frank during a sensory stimulation activity.

F: holds vibrator up to Jason's ear  
 J: turns head away from vibrator  
 F: "Hey, Hey, Hey, He flinched, He flinched, He flinched! (looks closely at J.) If you put it near his ear, he don't like that. He listened! I got his attention! (October 8)

In addition to responses elicited during structured sensory stimulation sessions, there appeared to be generalization of behaviors to other situational contexts. Jason turned his head toward the door when people knocked, looked up toward the barking loudspeaker above his bed, and shifted his eyes in the direction of the incessant screaming from the women across the hall.

In terms of auditory response to speech, during the second week of the post-implementation phase, Jason turned

his head and shifted his eyes toward the investigator when she called his name. A subsequent video-tape analysis revealed that Jason appeared to be "following" conversations between participants, visually and with head movements. On December 6, the SLP reported that Jason was exhibiting an increased rate of response to single stage auditory commands.

#### Visual Stimuli

On final administration of the WNSSP, Jason demonstrated bilateral horizontal tracking abilities, consistent downward eye movement, infrequent upward eye-movement and an overall increase in rate of visual response. Functionally, Jason evidenced these behaviors when tracking a flashlight, following interactants as they moved from one side of the room to the other, looking up when slides were directed toward the ceiling, and looking down when his arms were stimulated with a vibrator. During the first week of November, Jason's wife and son reported that he appeared to be watching television.

Investigator steps in front of T.V. to hand Frank sensory stimulation kit.

J: (head turned towards Inv.) vocalizes

M: "T.V. or Frank you're talking to?"

J: turns to May and then back to T.V.

M: "He's watching that damn Saints game."

(November 8)



## Additional Measures

### Affective Communicative Behaviors

Over the course of intervention, the gradual relaxation of Jason's facial musculature was accompanied by grinning, frowning, and smiling. Initially these behaviors were exhibited only with Frank, but they subsequently generalized to family members, therapists and the investigator. These affective behaviors were documented through video-tape analysis and participant reports. The SLP noted that Jason was demonstrating positive affective behaviors for the first time since his heart attack.

SLP: See that facial expression and the laughter, that's something I've never seen before. (November 14)

Jason also evidenced negative affective behaviors which served the purpose of protesting and regulating other participant's behavior.

F: (Places vibrator on Jason's shoulder)  
 J: frowns, turns head toward Frank  
 F: "Look at his face. That's the meanest look I've ever seen. That's it, That's a facial expression."  
 SLP: "He's getting irritated. That's a different face."  
 (Fieldnotes, November 11)

### Gestural and Augmentative Communication

As his voluntary motor repertoire increased, Jason began supplementing eye-blinks with natural gestures such as nodding his head or shrugging his shoulders. Additionally, augmentative techniques were incorporated

into sensory stimulation activities. On November 5, Jason spontaneously activated the Liberator during a session with Dan.

D: (Puts feather on Jason's face)  
 J: turn's head slightly, extends arm and activates device "Cut the shit"  
 I: "Alright, we will!"  
 M: "Jason, you didn't like that on your face?"  
 J: moves mouth, raises eyebrows. (November 5)

#### Vocalization and Verbalization

On October 8, Jason maintained a constant string of vocalization while Frank was interacting with the investigator. During the next session Frank commented on Jason's vocal behaviors:

F: Last time I was here, he was talking up a storm.  
 (October 14)

In addition to the noted increase in frequency of vocalization, Jason began initiating vocalization during intervention sessions and while other participants were conversing. The speech pathologist noted Jason had reduced his delays before responding and that vocalizations were more accurate or "sharper".

SLP: Definitely a change in response onset, it seems like he's reduced his delays before responding and they're now accurate or sharper and that goes with facial expressions locating towards the interactant.  
 (December 6)

A decrease in the delay of response onset contributed to the perception that Jason was turn-taking or exhibiting responses that were directly related to those of the interactants.

S: I really didn't realize until Ben mentioned it how when he's covered up and vocalizing that he's taking turns. (December 6)

The following excerpts taken from fieldnotes based on sensory stimulation sessions illustrate Jason's verbalizations at an imitative and spontaneous level of production.

Obs. Frank enters Jason's room.

J: turns head toward door  
"Hi."

I: "Oh my god!"

F: "That's the first time he said 'hi', huh?"

I: "Musta been that coffee."

F: "He said 'hi' distinctly when I heard him."  
(October 14)

Obs. Frank holds banana extract up to Jason's nose

SLP: "What's that smell like?"

J: "Ah Nah"

I: "Did you hear him say banana?"

F: "It was close enough for me." (Oct.22)

Obs: May sits to the left of Jason and Dan sits to the right during sensory stimulation.

M: "Ya wanna go home?"

J: purses lips, vocalizes, sounds like home

I: "Home?"

J: vocalizes, "ho"

I: "Home? Ya wanna go home?"

J: "ho"

I: "Can you say it one more time for me?"

J: string of vocalizations with rising inflection, "ye, ye, uh, huh, huh" (Oct.22)

### Motor Behaviors

Following eight weeks of communicative intervention, the occupational therapist provided the following summary of Jason's motor function. Jason exhibited increased head control and upper torso support, increased range of motion in the upper extremities, and flexibility of the lower extremities. He also demonstrated increased voluntary

movements of the upper and lower extremities and an overall decrease in hypertonicity. The reports of the occupational therapist were supported by descriptive observations and participant reports. For example, with decreased hypertonicity, Jason began extending his legs, leading to the following observation by his son: "The bed looks like it's shrinking up". The SLP, family members, and facilitators commented on Jason's increased head support and voluntary movements of the extremities. Participants also began reporting changes in Jason's voluntary motor behaviors.

M: He was moving that arm before. (Oct.18)

S: One thing he's doing more now. He's got those feet going. (Oct.22)

F: Look, now he's gonna turn his head. "Get that shit away from me". (Oct.30)

SLP: He's moving that shoulder. (Nov.18)

During a sensory stimulation session, Frank elicited and then commented on the following motor responses.

F: (Places vibrator on Jason's hand)

J: Pulls hand away and grimaces.

F: "He moved his hand and his mouth, We're aggravating the shit out of him now. (December 6)

The motor behaviors elicited via sensory stimulation activities appeared to generalize to augmentative technology sessions. On October 20, Jason activated the slide projector by raising and lowering his thumb to access a Wafer Switch (Tash). While responses were inconsistent, during subsequent sessions he turned his head or squeezed

his hand to activate a variety of switch operated appliances. On November 15, Jason was presented with the Liberator (Prentke-Romich), a high technology communication device. This electronic communication system had digitized speech output, and was programmed by the investigator with meaningful utterances that Jason could access by manually depressing one of eight cells (see Appendix J for sample overlay). When appropriately positioned with the device placed on a hospital tray, Jason exhibited adequate range of motion and flexibility of the wrist and hand to access all four quadrants of the device.

During the second month of the investigation the investigator discovered several variables that appeared to affect Jason's frequency of switch activation. First, Jason tended to consistently activate a wafer switch when pictures of bikini-clad women were included among slides of his home and family.

obs. Jason lays in bed, body turned toward the wall where the slides are directed. Jason is not activating switch so I have to press his thumb down every once in a while. After picture of the cousins, woman in yellow bikini comes up. Slides start progressing and I notice Jason is raising and lowering his thumb.

I: (to Jason) "Man, you have to come to Frank's room, see his posters (of naked women)"

F: "Compare your women with mine"  
(November 15)

Additionally, Jason responded more accurately when the required pattern of switch activation was related to past experience:

Obs: Jason lays in bed holding Wafer switch attached to the slide projector. Has not been too responsive.

I: "Activate that switch like you're lighting a cigarette"

J: immediately activates switch, progresses to next slide (November 15)

### Facilitator Behaviors and Interactions

It should be noted that Frank was considered the primary communication facilitator, participating in all scheduled intervention sessions and interviews. Dan participated in 12 intervention sessions; However, in mid-November he began experiencing health problems and was not available for final sessions or interviews.

#### Dan

During the sessions he attended, Dan consistently positioned himself close to Jason's and attempted to establish eye-contact. He also closely observed Jason and continued to exhibit a relaxed, natural interactive style.

D: (Holds up vanilla) "Remember that smell?"

J: blinks eyes

D: "Got another one coming up (Holds up crab boil). Shoo it's been a while, huh? Smell them big crawfish?"

J: "uh-huh"

I: "That'd go good with Old Milwaukee"

D: (to Jason) "Budweisers best." (Holds up "gravy") "Stick your tongue out, it's a nice juicy steak."

J: vocalizes

D: "Tell Frank to break out his bar-b-que pit (Holds up rum) Some J.D. Man."

J: appears to grin

D: "Looks like he cuts a smile once in a while too." (November 5)

Dan became increasingly inaccessible over the course of the investigation, often sleeping in his room or "not

feeling well". It was reported by the SLP that he entered a "hospital" and, consequently, was not available during the last two weeks of intervention. It was later discovered that Dan had a substance abuse problem and had been admitted to a treatment program.

### Frank

During the first two weeks of the post-implementation phase, Frank continued to physically distance himself from Jason during sensory stimulation sessions. On October 8, however, there were documented changes in Frank's interactive behaviors following an adaptive response from Jason.

Obs. Frank sits by Jason's bed, reaches out and holds almond extract up to his nose and then turns toward Investigator.

J: turns his head to Frank, vocalizes

F: (Looks surprised and turns back to Jason)  
 "I don't think I ever heard him say anything. That shocked me for a minute." (looks toward Jason with interest) "Go ahead and spit it out now."

J: vocalizes again (October 8)

Immediately following the above interaction, Frank began asking May questions about Jason's past, initiating interaction, and attending to his non-verbal behaviors.

F: "I've never seen a picture of Jason before the accident. I've never been curious, I never had, I just don't know."

J: vocalizes

F: "Lots of movement there. How old is Jason now?"

M: "42"

F: "Hey buddy"

J: no response

F: "Jason, Jason"

J: shifts eyes to Frank

F: "Alright Jason, Chow time."

J: moves tongue to lips  
 F: "Get that tongue out of here, Hey Jason, what's that taste like? beef?"  
 J: vocalizes (October 8)

Frank subsequently began greeting Jason, wheeling himself close to the bed and attempting to establish eye-contact at the beginning of each session. He was also observed frequently touching or playfully hitting Jason to gain his attention. Frank also appeared to observe Jason's behavioral responses closely during sensory stimulation activities and had the distinction of eliciting the first post-injury smile during a sensory stimulation activity.

J: lays in bed staring straight ahead.  
 F: (taps Jason on the shoulder) "Hey Rason, Rason".  
 J: slowly turns his head toward Frank and smiles  
 I: (laughing) "You called him Rason!"  
 F: "Whatcha doing bud? Whatsa matter? Ya don't like being called Rason? Hey it sounded natural to me." (October 14)

By the third week of intervention, Frank was consistently entering Jason's room shortly after the investigator arrived. During the fourth week, he waited outside for the investigator and informed her when she was late. As indicated by the following excerpt from the last two weeks of intervention, Frank became more animated and verbose when interacting with Jason.

Obs: Jason lays, head turned away from Frank. Frank repeatedly places vibrator on his arm.

F: "Ain't nothing I enjoy more than bugging the shit out of Jason. If he tells me to get the hell out of his face I'm gonna jump out of my skin. It's gotten where I don't enjoy nothing more. (starts tapping on his arm) It's time to wake up. Hey Jason, there can't be nothing I enjoy more than



annoying the shit out of you. Make my day, Make my day."

J: grimaces and pulls his arm away.  
(November 14)

An interesting opportunity arose for both facilitators during the first week of November. The activity director, hearing of their work with Jason, appointed Frank and Dan resident advocates. Frank described the new responsibility during the December 6 intervention session.

F: Dan and I are advocates... Man, I got so many people I'm helping it's pitiful. They all coming to me. Whenever a thing needs to be done, I get it done. If clothes are lost, I find them or buy um. That's what I'm here for. She (the administrator) don't like to see me coming. I've yet to fail yet. I've done everything they've wanted. (December 6)

#### Frank's Perspective

Dan was not available for the final interview on December 6; however, Frank's opinions about Jason's condition and expectations for further recovery were obtained. In regard to Jason's overall level of responsiveness, Frank offered the following opinion:

F: It's amazing how much awareness has come since I first started coming in. When I first seen Jason, I said, He don't know nothing but ya'll had to show me that he could do stuff. (December 6)

When asked about the efficacy of the model Frank responded positively, indicating that he had been partly responsible for Jason's response.

F: We have brought him along. When we started the program he has improved, a lot, a super lot. We've done some good. I mean I've seen that. That's clear enough to see on film. There has been improvement. When we first started he wasn't doing anything. (December 6)

Although Frank was positive about the service delivery model, he indicated that Jason was not yet ready to "learn" anything. He expressed that sensory stimulation and "visiting" might prove beneficial, but was unsure about any further potential recovery.

F: Stuff like coming and visiting that would help a lot, There ain't no doubt about that happening. Cause that's what my family was told to do. To get him in a situation of having to do things for himself, He's not that far along, not yet to do anything for himself. Things to bring him out of the coma. Those are the things that need to be done. (December 6)

#### The SLP

During the first month of the post-implementation phase, the SLP continued to emphasize speech production; however, he focused less on eliciting consonant-vowel combinations (CV) and progressed to bi-syllabic words. The following excerpt from a November 11 session is representative of post-implementation speech production activities.

SLP: "Jason, you ready to do some speech therapy? Some sounds? Maybe some talking about lemons? Say lemon, say lemon. Put your tongue in the air and say lemon."

J: moves tongue to edge of lips.

SLP: "Yeah, see your trying and that's good. Remember when we were working on that a couple of days ago? See if you can do it again. Say lemon. Say lemon, You want some lemon juice? Huh? You want some lemon juice?"

J: moves mouth

On December 6 the SLP was provided access to the sensory stimulation kit and proceeded to experiment with

the techniques. The following excerpts are taken from olfactory and tactile stimulation activities.

obs: SLP places Q-tip dipped in "kitchen bouquet" on Jason's tongue.  
 SLP: "Like the taste of beef?"  
 J: raises eyebrows  
 SLP: "Stick your tongue out."  
 J: after 30 second sticks out tongue.  
 SLP: "Vanilla extract, wanna try it?"  
 J: vocalizes  
 SLP: (sticks in mouth)

The SLP subsequently created his own sensory stimulation kit for use following completion of the investigation.

### Social Interaction

Video-tape analysis of social interactions between Jason and the SLP during the last two weeks of intervention revealed that the SLP took fewer conversational turns, decreased his length of utterance, increased pause time between utterances, and asked yes/no questions to which Jason was capable of responding.

SLP: "Hey Jason, you wonder where Frank is?"  
 J: turns head, vocalizes  
 SLP: "Jason were you mad when your roommate took a dump and we left you here?"  
 J: vocalizes  
 SLP: "The physical therapist is coming to evaluate you on Wednesday. If you tell me no we won't bring her."  
 J: vocalizes  
 SLP: "Good turn-taking. Alright, I'm gonna take off."  
 (November 15)

### The SLP's Perspective

When asked if Jason's responses during the post-implementation phase had affected his therapeutic goals,

the SLP indicated that there was more emphasis on interaction and communicative function.

SLP: My focus in therapy has been just doing more interactive stuff cause he's more responsive. Used to be taste stimulation, a little bit of conversation. Now it's sit down slowly and reasonable easy questions, try to get him to say "uh huh" or "no", maybe protest. (December 6)

In terms of the effects of Jason's responses on social interactions, the SLP noted a more evenly balanced pattern of interaction.

SLP: I think it's more reciprocal in the fact that I've started seeing him as a regular conversational interactant. Like a regular. (December 6)

The SLP indicated that the service delivery model was beneficial to Jason and Frank; However, he reported that Dan might not have been as motivated as Frank because his initial expectations were met so quickly.

SLP: I would say it can only help both ways you know. Big changes in Frank. Just from the reluctance, the fact he thought Jason was a lot more sick, bed ridden, infirm, and the fact that he realized a that this person even though severely impaired was able to respond. (December 6)

SLP: Maybe Dan wasn't motivated. With Dan you hit the ceiling quickly, where Frank saw reaction from what he was doing. It was more reciprocal and just built up more motivation and confidence. He's initiating tasks, and touched him. (December 6)

The SLP also reported that Frank had become somewhat of an expert and was able to share his experiences with the family in a "support-group type atmosphere.

### The Family

During the post-implementation phase, Jason's outside visitors were limited to his wife, son and infrequently other family members. May reported that Jason's mother did not visit because she felt Jason was "comatose", and was waiting for reports that he had "come out of it". The family members observed visiting Jason on three separate occasions during the post-implementation phase included 1) Jason's brother Ray, 2) May's brother Frank and Frank's wife and 3) Jason's two daughters and grandson. Jason's brother was present during a sensory stimulation with Frank. Throughout the session it was noted that he stood silently, approximately two feet from the foot of the bed, never directly addressing Jason or approaching bedside. Ray did, however, indicate that Jason noticed him.

M: "Jason, did you say hi to Ray?"

R: "He looked at me a couple times." (October 14)

May's brother Frank and his wife were present during an assistive technology session with Dan. They positioned themselves far from the head of Jason's bed, and interacted mostly with May. Frank's wife observed intervention for a few minutes and then loudly asked May:

FW: "Can he see and hear everything?"

M: nods

FW: "Well if they keep bringing this in we can bring tapes of the kids and stuff. Cause we bought some tapes but we never did it. We could get Ashley to sing on it.

(pauses) Think he knows what's going on?"  
(October 22)

Jason's daughters and grandson visited on a day when no facilitator intervention was scheduled. The girls, 18 and 21, interacted naturally with Jason throughout the visit as he lay staring at the wall. Jason's grandson, Ken, talked almost non-stop to his "grandpa" telling him about his day and attempting to sit on his lap.

K: "Grandpa, Grandpa I saw a bird!"  
 J: (no response)  
 K: "Grandpa, I saw a bird and it talked!"  
 J: (no response)  
 K: "Grandpa, can I sit on your lap? Can I PaPa?"  
 J: (slight grin)  
 M: "He's peeing that's why (he's grinning)"  
 K: "Papa peed on himself? (looks surprised)"  
 K: (Because Jason was not responding) "We're gonna leave!"  
 M: (laughs) "That doesn't work with adults."  
 (October 26)

### May

During the post-implementation phase, May continued to frequently comment on Jason's medical status, physical condition, appearance and grooming.

M: I tried to clean out his nose and he got pissed and it was like, man, is there anything I can do that you like anymore? (November 6)

During intervention sessions she referred to his use of augmentative techniques as "playing" and often described his responses in terms of infant behaviors.

M: Found something else to play with huh babe?  
 (October 23)

M: He was fussing yesterday when ya'll sat him up.  
 (November 15)

It was noted, however, that May began responding to and acting on Jason's non-verbal signals as evidenced by the following interactions.

Obs: Prior to intervention session Investigator brings radio to resident across the hall.

J: Turns head to door

M: "What babe? Is that your radio?"

J: continues to stare at door

M: "Tell Alisa to bring it back over here"

J: vocalizes

Obs: During sensory stimulation session, Frank holds peppermint to Jason's nose, Jason closes his eyes, grimaces.

M: "Twenty more minutes and I get to move him on his back. Maybe he'll feel better then."

J: vocalizes, grimaces

M: "Oh, you want to go on your back now."

J: vocalizes

I: "Ya gotta tell her"

J: "Uh huh"

M: (Starts turning him over) "Don't give me a mean look, I'm the one who turns your butt." (October 30)

Obs: Prior to intervention session, Jason, May, SLP and Investigator in room.

J: grimaces, looks down

M: "It's his splints"

J: vocalizes

M: "You want them off?"

J: vocalizes

M: "Okay, I just put them on, but I'll take them off." (Nov.18)

There were also several instances of sustained interaction between May and Jason documented during the post-implementation phase as illustrated in the following excerpt taken from a sensory stimulation session with Frank.

F: holds vibrator to Jason's cheek

M: "What's that remind you of?"

J: vocalizes

M: "Ya gonna talk to me with that?"

- I: places vibrator in Jason's hand, holds to May's cheek  
 J: Grins  
 M: "Look at him-He's gonna laugh at me about this. You think you're something special."  
 J: continues grinning, vocalizes

In addition to employing more facilitative interactive strategies, May began providing Jason stimulation by playing music, leaving the television on during the day, and opening the window shade above Mr. F's bed before each post-implementation intervention session. The SLP reported that May was also beginning to incorporate some of the novel sensory stimulation techniques.

SLP: She's been good about mimicking what you do in therapy, she has really. She mentioned that today about that, what you were doing. (December, 6)

#### May's Perspective

During a final interview, May indicated some of Jason's pre-morbid behaviors were beginning to emerge.

M: Ben (the SLP) even noticed it. He's starting to get his self back like the expressions on his face, trying to talk, moving his arms a lot more. (December 6)

She also reported that the responses Jason exhibited during sensory stimulation sessions carried over to other situational contexts and noted distinct benefits in employing facilitators rather than relying solely on professionals.

M: They're just ordinary people and they're men and they all got things in common with him. They can also give an objective opinion. We try to look for things that aren't really there. I think with Frank, it's good for him. He can almost imagine what he went through. It made me feel good cause Frank said it



gave him something to do. He has a purpose, he's doing good for Jason. (December 6)

Finally, May suggested that Jason appeared motivated by the change in his daily routine and novel activities provided by facilitators.

M: I notice on the days where he don't get that therapy you're giving him, the smelling and stuff, he misses that, like he waits for it. He looks like he got into a routine and then one part of the routine is gone. (December 6)

### The Son

During the post-implementation phase, Jason's son took part in many of the facilitator-directed activities. While Frank or Dan employed sensory stimulation techniques, Jason Jr. informed them of changes in Jason's behaviors, and encouraged Jason to respond.

S: "A little while ago I was brushing his hair and I asked him to hold his head up and he did."  
 F: "Uh huh" (holds up peppermint)  
 S: "Can you smell that."  
 J: turns head away from Frank.  
 S: "Can you look at Frank and tell him to stop?"  
 J: turns head toward Frank, vocalizes  
 F: "Ya like that?"  
 J: looks at Frank  
 S: "Daddy, Daddy, mama tell you the Saints are going to the play offs?" (November 3)

### The Son's Perspective

During a final interview, Jason's son noted that the emergence of affective behaviors improved the quality of interactions with his father.

S: He kinda lets you know with facial expressions and you try to guess what he's saying and everything. His face lets you know if you're right or wrong right off the bat. Smiling and all, that's pretty much the biggest change. (December 6)

When asked his opinion of facilitators, Jason Jr. indicated that he was initially disheartened by Frank's low expectations and was surprised when he turned out to be an effective facilitator.

S: I kind of thought that Frank would be a sore spot, but I noticed when he was poking him on the shoulder he got really excited. Dan, he goes up in there but he don't have that macho. (December 6)

### The Staff

Jason's wife and son reported several instances where nurses responded to Jason's non-verbal communicative behaviors and commented on changes in the interactive behaviors of other staff members.

M: Debbie asked if he wanted coffee, so he said uh huh and she gave him coffee. (Interview, October 30)

S: A nurse came in the other morning and saw Jason looking at the water pitcher, so she gave him some water. (Interview, October 30)

S: I have noticed lately that most of the workers here come in the room and talk to him. They used to come in and ask us how he's doing. Especially that woman in housekeeping said she didn't even know it was the same person. (December, 6)

M: I know all the aides say he makes all sorts of sounds to get your attention. When they came in before they said he just stared straight and now he follows them. (December 6)

In addition to these reports, the investigator observed a nurse responding to Jason's "verbal" communicative signal. This occurred during an augmentative session with Frank when Jason was provided with The Liberator. The device, which was equipped with "Handsome Harry" (DecTalk) digitized speech, had been configured with eight phrases

reflecting Jason's personality and style of speaking (eg. "I love you May", "Cut the shit", "I need a drink", "I've gotta get out of this place").

Obs: Nurse enters room, fills water pitcher and turns to leave. Loud screaming from across the hall.

J: activates device  
"Who the hell is that screaming and why the hell won't she shut up?"

N: (turns around with startled look, stares at Jason)  
"Why that's Mrs. Jones across the hall."  
(shakes her head and leaves the room).  
(November 5)

The Investigator also had an opportunity to observe an interaction between Jason and a lab technician from the local hospital when Jason began experiencing problems with the circulation in his legs. The following excerpt taken directly from fieldnotes describes the technician's behavior during the session.

The 50 minute procedure entailed encasing Jason's legs and toes with bands that measured the pressure of arterial blood flow. The technician did not explain the procedure, look at, or interact with Jason at any point during the session. Jason, on the other hand, appeared tense with wide eyes and open mouth. (October 13)

Interestingly, ten days after his initial visit, (October 23) the same technician performed another arteriogram. The investigator was not present, however, Jason's wife reported that the technician entered the room, looked at Jason and informed her that Jason seemed more "aware", "like a different person". May reported that the

technician explained the procedure to Jason and "spoke to him" the whole time.

### Staff Perspectives

When asked her opinion about the facilitator-based model, the activity director indicated that it was a positive experience for Jason, Frank, and "everybody":

AD: Believe it or not everybody is involved. It's because the state this man was in when he first came. To see this man, It's like everybody wants to get behind him and push him on. Come on, you can do it. This man is going to go home. Otherwise we're gonna have a miracle right here... Frank being a resident, being in a wheelchair himself, I think it inspires him too. Maybe then too Frank came a long way himself. I think sometimes he looks at Jason and he sees himself. (November 14)

Additionally, she described how Jason's success had modified her own perspective.

AD: It's good for me cause it tells me when we get one in here regardless of what state they're in, it don't have to be that way. (November 14)

Interestingly, following the interview, Jason's wife noted that the Activity Director had not yet visited Jason's room or re-assessed his case.

### The Investigator

During the post-implementation phase the investigator became more familiar with Jason's pre-morbid personality and adapted to his level of responsiveness. The following excerpt is taken from data documented toward the end of the investigation when she was again left alone with Jason while administering the WNSSP.

J: stares at investigator's stomach  
I: "Don't look at that baby, he didn't do  
anything to you, it's me that's bugging the shit  
out of you!"  
J: slowly looks up at my face and smiles.  
(November 17)

### The Roommate

There were no observed interactions between Jason and his roommate during the post-implementation phase. During the second week of October, however, Mr. F. began sitting up in bed and observing facilitator-directed intervention sessions. On October 30, the following observation was recorded in fieldnotes:

Frank enters the room and wheels himself to right side of Jason's bed. Mr. F. is sitting in the orange chair next to Frank, staring at him while chewing on candy taken from a big bag in his lap. (October 30)

During each subsequent session in which he was present, Mr. F. sat up in bed or in the orange chair and observed the events on the other side of the room.

## CHAPTER V: DISCUSSION

This investigation was designed to evaluate the efficacy of a facilitator-based model of communicative intervention which incorporated sensory stimulation and augmentative techniques to effect changes in the behaviors of a STR brain-injured adult. Additionally, the investigator sought to determine, through ethnographic methods, if the training of two nursing home residents to act as communication facilitators and subsequent implementation of intervention would lead to secondary changes in the subject's communicative environment. Comparison and analysis of quantitative and qualitative data documented during both phases of the investigation indicate that the service delivery model was effective in that the goals of intervention were met: there were positive changes in Jason's cognitive, communicative, and motor behaviors. Moreover, there appeared to be a complex, dynamic relationship between Jason's emerging responses, the perspectives and interactive behaviors of other participants, and various aspects of the social setting. The findings of this investigation will be discussed in terms of Jason's behaviors, facilitator variables, and secondary changes in the behaviors and interactive patterns of other participants within the communicative environment.

### Changes in Subject Variables

During the pre-implementation phase of the investigation (7/8/92 - 9/21/92), Jason's apparent lack of environmental awareness and minimal response to external stimuli posed substantial barriers to rehabilitative efforts and greatly interfered with attempts by the investigator, facilitators, and other participants at social interaction. The extent of non-responsiveness was reflected in the conflicting diagnoses of physicians and descriptions of Jason by staff, therapists and family members as both comatose and existing in a PVS. At this stage, there was little evidence that Jason was able to process, interpret, or respond to various types of environmental stimuli, and there was little hope for re-establishing communication or remediating higher-level cognitive processes.

It was hypothesized that the introduction of sensory stimulation techniques would facilitate neural recovery, thereby enabling Jason to process and respond to information of increasing variety and complexity. Additionally, it was anticipated that motor responses elicited through structured sensory stimulation would allow Jason to control aspects of his environment via augmentative techniques. Data collected during post-implementation phase of the investigation (9/22/92 - 12/6/92) support these hypotheses.

### Response to Sensory Stimulation

A comparison of the pre-implementation and post-implementation results of the WNSSP reveals that quantitative changes occurred within each of the following subscales: Arousal/Attention, Auditory Response, Expressive Communication, Visual Response, Tactile Response, and Olfactory Response (see Table 8). An overall increase from the pre-implementation mean score of 22/113 to the post-implementation final score of 59/113 indicates that Jason progressed from a non-purposeful, generalized level of response to a more localized pattern with specific responses directly related to the stimuli presented.

The time frame in which adaptive behaviors emerged was somewhat surprising. Further examination of Table 8 reveals increases in ease of arousal, eye-contact, auditory response to voice, and horizontal visual tracking responses at the end of the first week of the post-implementation period (10/1/92). Additional responses to olfactory and tactile stimulation, as well as increased vocalization, were documented during the second week of intervention (10/8/92). These quantitative findings were supported by video-recordings and participant reports of changes in responsiveness and emerging communicative behaviors.

It is not possible to determine the extent of neurological recovery; however, the rapidity of these changes suggests Jason may initially have been



Table 8  
Pre-Implementation and Post-Implementation Results of WNSSP

MODALITIES	9/21	10/1	10/8	10/14	10/22	10/30	11/6	11/14	11/19	11/27
I AROUSAL/ATTENTION										
1. arousability	1	2	2	2	3	3	3	3	3	3
2. wakefulness	1	1	2	2	2	2	2	2	2	2
3. eye-contact	1	2	2	2	2	2	2	2	2	2
4. attention to task	0	0	1	1	1	1	1	1	1	1
II AUDITORY RESPONSE										
Localization										
5. voice	1	2	2	2	2	2	2	2	2	2
6. sound	1	1	2	2	2	2	2	2	2	2
Comprehension										
7. shake hand	0	0	0	0	0	0	0	0	0	0
8. opn/cls mouth	2	2	0	2	2	2	2	4	2	4
9. stk out tongue	2	2	0	2	2	4	4	2	4	2
10. opn/cls eyes	2	2	2	4	4	4	4	4	4	4
11. raise eyebrows	0	0	0	0	0	0	0	0	0	0
12. move body part	0	0	2	2	2	2	2	2	3	3
III EXPRESSIVE COMMUNICATION										
13. vocalization	1	1	3	1	1	3	3	3	3	3
14. facial/gest response	0	0	1	2	2	2	2	2	2	2
15. yes/no	1	1	1	1	1	1	1	1	1	1
IV VISUAL RESPONSE										
16. hor trk: mirror	0	1	1	2	2	3	3	3	3	3
17. hor trk: individual	1	1	2	2	2	3	3	3	3	3
18. hor trk: picture	0	1	2	2	2	3	3	3	3	3
19. hor trk: obj	0	1	2	2	2	3	3	3	3	3
20. vert trk: mirror	0	0	1	1	1	1	1	1	1	1
21. vert trk: individual	0	0	1	1	1	1	1	1	1	1
22. vert trk: picture	0	0	1	1	1	1	2	2	2	2
23. vert trk: obj	1	1	1	1	1	1	2	2	2	2
24. opn/cls mouth	2	2	0	0	2	2	0	2	2	2
25. stk out tongue	2	2	2	2	2	2	0	2	2	2
26. raise eyebrows	0	0	0	0	0	0	0	0	0	0
27. move body part	0	0	0	0	1	1	0	0	0	0
V TACTILE RESPONSE										
28. touch	1	1	2	2	2	2	2	2	2	2
29. oral stimulation	1	1	1	1	2	2	2	2	2	2
30. obj. manipulation: spoon	9	9	9	9	9	9	9	9	9	9
31. obj. manipulation: comb	9	9	9	9	9	9	9	9	9	9
32. obj. manipulation: penc	9	9	9	9	9	9	9	9	9	9
VI OLFACTORY RESPONSE										
33. smell	1	1	2	2	2	2	2	2	2	2
TOTAL SCORE	22	28	38	44	49	57	54	58	59	59

"underfunctioning" or exhibiting less than optimum responses within his communicative environment. Calculator and Luchko (1981), attribute underfunctioning in non-verbal individuals to insufficient motivation to communicate, lack of availability of conversational partners, infrequent opportunities to communicate, lack of reason to communicate, and lack of responsiveness to attempts at communication. Based upon qualitative data documented during the pre-implementation phase, it is conceivable that environmental, social and psychological variables interacted with Jason's already damaged nervous system and prolonged period of passivity, thus lowering his initiative or drive to respond. Conversely, the introduction of structured sensory input, novelty of peer interactants, and modifications to daily routine (environmental enrichment) may have effected positive physiologic and psychologic changes. Regardless of the underlying mechanism responsible for these changes, Jason's emerging adaptive behaviors had significant therapeutic and interactive implications.

#### Differential Diagnosis

During the pre-implementation phase, it was difficult to determine whether Jason was actually STR, comatose, or existing in a PVS. He demonstrated periods of wakefulness; however, it has been reported that arousal can occur with only brain stem function and in the presence of complete

destruction of both cerebral hemispheres (Berrol, 1986). The factor which distinguishes STR from the other non-responsive conditions is "awareness", or the cognition of self and the environment, as this implies functioning within the cerebral hemispheres with some content and ability (Ansell, 1991).

The sensory stimulation techniques utilized by facilitators during the post-implementation phase elicited adaptive behaviors from Jason which signalled some degree of cognitive awareness. For example, a decrease in primitive, vegetative oral movements during olfactory and gustatory stimulation, and the subsequent emergence of localized, differentiated responses (i.e., verbalization, affective behaviors, head turn) indicated that Jason was no longer merely responding on a reflexive, subcortical level. Through visual tracking behaviors and localized responses to auditory stimuli, Jason began selectively attending to objects and interactants and shifting attention between environmental events. With increased rate of response it became evident that Jason was following single-stage commands with some degree of consistency. Perhaps the most significant changes which occurred during the post-implementation phase, further distinguishing Jason as STR, were in the expressive and receptive communicative behaviors initially manifested during sensory stimulation

activities and subsequently generalizing to other situational contexts.

### Communicative Behaviors

Analysis of data documented via the WNSSP, video-recording and observation during the pre-implementation phase revealed that Jason did not initiate interaction, respond to interactive efforts, or demonstrate functional communicative abilities. Additionally, the absence of affective behaviors and natural gestures contributed to an "abnormal" posture that was not highly conducive to interaction. During the post-implementation phase, however, Jason demonstrated increases in: 1) rate of response, 2) initiation of communicative behaviors, 3) vocalization and verbal approximation, 4) affective behaviors, and 5) non-verbal signalling behaviors. Initial changes were documented during the second week of the post-implementation period as Jason visually attended to Frank during sensory stimulation sessions. He subsequently began turning his head toward other speakers and visually "following" conversations between participants. In addition to contributing to a more natural, albeit far from normal, interactive posture, emerging signalling behaviors enabled Jason to effect changes in his communicative environment.

While Jason produced consonant-vowel (CV) combinations during the pre-implementation phase, these vocalizations

appeared to serve no communicative function. During the post-implementation phase, however, increasingly complex vocalizations and verbalizations served the functions of protesting, commenting and greeting. The factor that appeared to be most conducive to social interaction was the emergence of affective communicative behaviors. An overall relaxation of the facial musculature, accompanied by grinning, smiling and frowning, humanized Jason to some extent and reinforced the perception that he was "aware" and responsive to his surroundings.

#### Response to Augmentative Techniques

During the pre-implementation phase of the investigation, Jason's lack of voluntary motor response, hypertonicity, frequent clonic muscle spasms, and contractures left him little flexibility to implement a functional conventional or gestural communicative system. Moreover, the subtle motor responses in his repertoire were not sufficient to control any aspect of an environment which was not adapted to minimize his limitations. As noted in the Review of the Literature (Chapter 2), profound helplessness and loss of control may decrease motivation and contribute to a state of learned helplessness (Seligman, 1975). It was anticipated that the responses elicited through sensory stimulation could be shaped and utilized to access microtechnology, thus reinforcing contingency awareness, providing some degree of control,

and possibly interrupting the cycle of learned helplessness.

The increased head control, overall relaxation of the musculature, reduction in muscle spasms and contractures, and voluntary motor behaviors Jason exhibited during the post-implementation phase greatly affected his potential to access assistive technology. In fact, based on his initial motor responses during olfactory and tactile stimulation the investigator anticipated that head turn or hand movement would eventually become Jason's most consistent and reliable motor responses. Unfortunately, while he demonstrated the minimal motor abilities needed to access simple technology, Jason did not appear highly motivated to engage in microswitch activities. Although there was a documented increase in the frequency of switch activation during activities which incorporated the slide projector, adapted appliances, message and conversation tapes, or music, these responses were inconsistent. Toward the end of the investigation, however, Jason consistently activated the Liberator (Prentke Romich) on three separate occasions via direct selection with his left upper extremity. His ability to access the Liberator was unexpected, as dedicated or high tech communication devices are seldom, if ever, considered appropriate for individuals functioning at Jason's apparent cognitive level (DeRuyter and Kennedy, 1991). It was not clear whether initial activations were

incidental, however, it appears that contingent social response from other participants was more motivating to Jason than the object reinforcers incorporated in switch activities. This finding is consistent with Schweigart's (1989) observation that profoundly brain injured persons respond more frequently, consistently and with greater generalization to activities which combine assistive technology with social outcomes. Additionally, by activating the Liberator during intervention sessions, Jason was able to initiate social interaction and effectively gain attention, which are the initial stages in Schweigart's (1989) Early Communication Process (ECP) outlined in Chapter 2 (Review of the Literature).

Light (1988) suggests that communication by non-speaking physically disabled persons should not be restricted to the use of an AAC aid; rather it should be a multimodal process that includes vocalization, gesture, sign, eye-gaze, and facial expression. Thus, it should be noted that while there was an emphasis on the implementation of aided communication techniques or mechanical devices during the post-implementation phase, these were considered only one component of Jason's total communication or multimodality system. He was clearly more successful and motivated when utilizing readily available unaided or natural communicative signals such as vocalization and facial expression to affect his

environment. This was not unexpected based on the findings of numerous researchers in the field of AAC that non-speaking persons tend to prefer unaided modes of communication rather than communication boards and technical aids (Calculator & Dollaghan, 1982; Culp, 1982; Harris, 1982; Light et al., 1985; Blackstone & Cassett-James, 1984). Nonetheless, Jason's minimal ability to access a variety of augmentative techniques, along with the emergence of unaided signalling behaviors provided several communicative options which were not available during the pre-implementation phase.

#### Prognosis for recovery

Changes in the complexity of Jason's response to external stimuli and the emergence of communicative behaviors during the post-implementation phase signalled some degree of "improvement". It should be noted, however, that "improvement" is used in the broadest sense--any increase in responsiveness or functional abilities. Jason continued to evidence profound neurological deficits, physical limitations and complex medical needs at the end of the investigation. Additionally, the etiology of anoxia, initial slow rate of change, and lengthy non-responsiveness are predictive of generally poor recovery (Ansell and Keenan, 1989a; DeRuyter & LaFontaine, 1987).

Regardless of the prognosis for recovery, Jason's responses to the techniques utilized during intervention



had significant therapeutic implications. Ansell and Keenan (1989) note that patients who consistently respond to stimuli, even if the responses are inappropriate, are often considered candidates for rehabilitation programs, whereas those who do not, tend to remain in long-term care facilities. A review of the literature supports this observation, as patients demonstrating generalized responses are rarely discussed in terms of therapeutic intervention or communication augmentation, while those who exhibit localized responses are considered appropriate candidates for early cognitive rehabilitation (Szekeres, et. al, 1985; Hagen, Malkmus and Durham, 1979) and simple communication boards and technology (DeRuyter and Kennedy, 1991). Ansell and Keenan (1989b) also note that improvement from level II (generalized response) or III (localized response) of cognitive function to level V (confused-inappropriate responses) on the Ranchos Los Amigos Scale, may be sufficient to allow for home care, an outcome which they report is decidedly less expensive than full-time skilled nursing. Jason did not progress to a level of consistent response within all situational contexts; however, he clearly demonstrated some potential for further recovery.

#### Facilitator Variables

As communication facilitators, Frank and Dan's roles were two-fold. First, they were trained by the

investigator to act as intervention agents, supplementing Jason's ongoing, traditional rehabilitation program with structured sensory stimulation and access to assistive technology. Second, they were considered novel peer interactants, providing new experiences and communicative opportunities. It was also anticipated that as nursing home residents, the men might find inclusion in the study to be a motivating and rewarding experience. Through ethnographic methods, the investigator sought to determine not only if Frank and Dan could facilitate changes in Jason's behavior, but what characteristics defined a successful communication facilitator.

Data collected via observation and interview during the pre-implementation phase revealed that the men were clearly very different in terms of background, personality, interactive style and perspective. Dan had substantially more contact with Jason and voiced relatively high expectations for his recovery. Frank, on the other hand, had minimal contact with Jason and reported he was "comatose-like". These differing perspectives were further evidenced by a pattern of interaction which emerged during the training period and continued through the first week of intervention. Frank frequently stressed the importance of family members not "getting their hopes up" and questioned Jason's potential for "learning". Dan argued that the family was realistic and assured Frank that Jason had some

potential for improvement. Thus, based on initial observation and interviews, the investigator anticipated that Dan, with higher expectations, would be a more motivated and effective communication facilitator.

#### Response to Training

Light et al. (1992) suggest that there is a great deal of individual variation across communication facilitators in terms of their response to instruction. Thus, in order to meet the facilitators' differing experiential and intellectual needs, the investigator individualized training by obtaining and utilizing information from Frank and Dan regarding their personal history and knowledge base. Pre-implementation data indicates that while the men approached training with unique perspectives and varying degrees of interest and motivation, both exhibited similar reactions and learning styles and appeared to relate to Jason's loss of control and independence. In terms of comprehending the material presented during informational sessions, it was noted that neither facilitator asked questions or provided feedback relating to brain injury or sensory stimulation techniques. Both, however, appeared to be intrigued by use of assistive technology, asking detailed questions, manipulating and experimenting with mechanical objects.

### Application of Sensory Stimulation Techniques

During the post-implementation phase, Frank and Dan quickly mastered sensory stimulation techniques and were able to elicit unique responses from Jason via structured sensory input. In addition to Jason's increased responsiveness, analysis of qualitative data documented during sensory stimulation activities yielded an unexpected interactive finding. It appears that the initiation (i.e., presenting extracts) and response (i.e., vocalization) sequence necessitated by the activities established a natural pragmatic framework (turn-taking) for interaction. With the focus diverted from linguistic content, facilitators were able to "ease" into interaction without the burden of generating novel topics or questions to elicit response. Initially, any response to the stimuli from Jason was acknowledged by the facilitators. If there was no response, however, the men were able to immediately progress to new "topics" or stimuli. By the third week of intervention it was noted that the initial rigid initiation/response sequence had changed into a more natural pattern of interaction, with both facilitators spontaneously generating conversation and attempting to relate stimuli to Jason's past preferences.

### Application of Assistive Technology

While successful with sensory stimulation, neither facilitator was able to independently employ augmentative

techniques with Jason. Analysis of qualitative data documented during these activities enabled the investigator to identify the following variables which may have contributed to their difficulties: Jason's lack of response to simple technology, the physical limitations of the facilitators and the complexity of the task given Jason's varying level of response and positioning.

As previously noted, Jason did not appear highly motivated by microswitch technology used to control appliances or devices during either phase of the investigation. Consequently, his lack of responsiveness appeared to inhibit the facilitator's attempts to initiate switch activities. Furthermore, as Jason became more responsive to sensory stimulation techniques, there was a tendency on the part of the investigator and facilitators to emphasize stimulation activities over assistive technology.

Another factor that interfered with the employment of augmentative techniques was positioning. On the one hand, Frank and Dan's confinement to wheelchairs allowed them to interact with Jason as equals, at eye-level. In terms of applying assistive technology, however, their positioning was a liability. Because Jason could not tolerate sitting in bed for any length of time and had no access to a wheelchair, the facilitators were forced to employ augmentative techniques while he was lying in bed. With

their limited range of motion and without optimum positioning the men had limited access to Jason's potential switch sites.

Finally, the implementation of augmentative techniques was relatively complex in that different strategies had to be employed based upon Jason's level of responsiveness. It appears that the constant re-adjustment and switch manipulation required to optimize Jason's performance proved too difficult for the facilitators. Moreover, the potential complexity and variability of the task was not addressed by the investigator during training sessions because Jason was primarily non-responsive at the time. It should be noted, however, that while unable to independently manipulate the switch paraphernalia, Frank and Dan were active participants during microswitch activities, serving as novel peer interactants, attempting to include Jason in conversation and evoke his interests.

#### Overall Efficacy of Facilitators

Both Dan and Frank were considered by the investigator to be appropriate and capable choices for communication facilitators as they could relate to Jason's loss of independence and control, had experience with assistive technology to control their surroundings and interacted with Jason as a peer rather than child or patient. Surprisingly however, with Frank's low expectations and initial interactive behaviors, he was a highly effective

communication facilitator. Dan, on the other hand, though able to elicit responses from Jason, was not quite as successful. The design of the study enabled the investigator to identify several factors which may have contributed to differences in facilitator efficacy. The first relates to interactive behaviors.

#### Facilitator Interactions

During hands-on training and throughout the first week of the post-implementation phase, the facilitators' verbal and non-verbal behaviors appeared to be guided by familiarity with Jason and expectations for response. Dan maintained a comfortable posture and natural interactive style whereas Frank demonstrated unusual proxemics and near avoidance of Jason. Interestingly, while facilitator training did not emphasize strategies for communicating with non-responsive individuals, Frank and Dan naturally progressed into more effective interactive patterns during the post-implementation phase. There were documented changes within each dyad; however, interactions between the individual facilitators and Jason were qualitatively different.

Modifications in the dynamics of interaction between Jason and Dan appeared to be primarily related to Jason's emerging communicative behaviors (i.e. increased rate and frequency of response). Dan maintained approximately the same structure of interaction during the post-

implementation phase, however, as he gained familiarity with Jason, he began relating stimuli to past preferences (i.e. Jack Daniels, steak), and attending to and commenting upon non-verbal behaviors. Within the Frank/Jason dyad, there was a more dramatic and reciprocal relationship between Jason's increased responsiveness and modifications in Frank's communicative behaviors. As documented in the Results (Chapter 4), initial changes occurred on October 1, following Frank's observation of Jason's increased awareness. He subsequently began directing most of his conversation toward Jason, attending to and interpreting non-verbal signals, and "goading" Jason to respond. Jason in turn, appeared to be motivated by Frank's social reinforcement, verbosity, humor, and playful teasing. From the second week of intervention Jason appeared to be more responsive to Frank than any other observed interactant. One can only speculate, but Jason's responses may have been motivated by Frank's booming voice, bright red hair, and motorized wheelchair, as all were novel stimuli in his environment.

#### Facilitator Expectations

In addition to Frank's dynamic presence, differences in facilitator efficacy appear to have been related to changes in expectations and demands for performance. Dan's expectation that Jason would intermittently respond to intervention was met during the second week of



intervention. He did not, however, increase his demands for performance to correspond with Jason's emerging capabilities. Frank, on the other hand, initially expected no response and consequently appeared to be surprised and motivated by Jason's increased awareness and emerging communicative behaviors. Uncertain of the limits of Jason's capabilities, Frank continually increased his demands for performance, but not to a point of frustration. It is conceivable that this "forcing" engendered a competitive spirit in Jason. Dan's easy-going nature, on the other hand, may have worked against him in that he was unable to generate a spirit of competitiveness.

#### Individual Characteristics

The final factor that appeared to affect Jason's response to the facilitators was personality differences. Comparisons between a tape-recording of Jason "partying" prior to his heart attack and ongoing video and audio recordings of Frank revealed similarities in voice, personality, and interactive style. Both were highly sociable and humorous, spoke loudly and rapidly, and used abrasive language. Furthermore, Frank frequently referred to his own brain injury and rehabilitation, and related his experiences to Jason. Dan, on the other hand, differed from Frank in that he was "low key", relaxed, and seldom displayed a sense of humor. Thus, it is conceivable that

Jason was more motivated by Frank's behavior and personal experience with brain-injury.

#### Facilitator Benefits

Data collected during the post-implementation period indicate that inclusion in the study was clearly more beneficial to Frank than it was to Dan. Whereas Frank demonstrated increased motivation corresponding with Jason's emerging responses, Dan became progressively evasive. This was attributed in part to failing health and a persistent drug problem. However, he also was not rewarded with the same degree of response from Jason as Frank. Frank, on the other hand, demonstrated improved memory, assumed some degree of responsibility, became introspective about his own brain injury and was able to share his own experiences with family members. Overall, staff, therapists, and family members reported that the facilitator-based intervention model was beneficial to both Frank and Jason. Unfortunately, the only perceived benefit to Dan appeared to be the role of patient advocate which came about as the result of his participation in the study.

#### The Communicative Environment

The quantitative and qualitative changes in Jason's behavior during the post-implementation phase have been largely attributed to sensory stimulation, augmentative techniques, and facilitator variables. There is additional need, however, to account for the behaviors and interactive

patterns of other participants in the communicative environment as partner-related variables appeared to have affected Jason's performance during each phase of investigation.

Qualitative data obtained during the pre-implementation phase indicate that Jason's lack of responsiveness was clearly the most significant barrier to interaction with other participants in his communicative environment. However, as previously noted, his rapid response to facilitator-based intervention indicate Jason may initially have been underfunctioning or exhibiting less than optimum performance during administration of the WNSSP and in other, informal situational contexts.

Underfunctioning in STR or non-responsive individuals has not been discussed in the literature, but has been reported frequently among individuals with severe disabilities who use AAC systems ( Calculator and Dollaghan, 1982; Houghton, Bronicki and Guess, 1987; Calculator 1989). Researchers in the field of AAC recognize that in addition to physical and environmental limitations, the motivation and communicative abilities of non-verbal individuals are often affected by the interactive styles and strategies of speaking partners (Kraat, 1985; Light, 1988), access to communicative opportunities (Halle, Baer & Spradlin, 1981) and instructional or therapeutic techniques (Calculator, 1988).

In Jason's case, the above variables appeared to operate along with cognitive and motor deficits to perpetuate underfunctioning and communicative passivity during the pre-implementation phase.

#### Pre-implementation Interactions

As discussed in the Review of the Literature (Chapter II), problems inherent in interactions between natural speakers and AAC users include asymmetrical patterns of turn-taking, initiation, and conversational control with speaking partners dominating interaction (Light, 1988). The characteristics of interaction between natural speakers and non-responsive individuals have not been addressed in the literature, however, results of this study indicate that many of the problems documented with natural speakers and AAC users exist on a larger scale.

Data collected during the pre-implementation phase reveal that while Jason came in contact with many potential interactants over the course of each day, there was very little effective communication taking place. Moreover, the interactive styles and strategies of participants often interfered with Jason's opportunities to initiate or respond to interaction. For example, pre-implementation social interactions between Jason and the SLP were characterized as highly nonreciprocal with the therapist taking a disproportionate number of turns, demonstrating minimal pause time, and asking open-ended questions that

Jason was incapable of answering. The linguistic complexity of his messages and rapid-fire style of interaction allowed Jason minimal opportunity to process, respond to, or initiate communication.

The nature of therapeutic techniques may have also contributed to Jason's less than optimum performance during pre-implementation observations. As suggested by Calculator (1988), rather than instilling an appreciation of communication as a means of having an impact on their environment, therapists often encourage clients to repeat modeled forms that have little communicative significance. This was clearly the case with the SLP who emphasized speech production over re-establishment of functional communication and used meaningless, sometimes aversive stimuli (i.e., lemon juice) as "reinforcement" for communicative efforts. This "mistaken focus" of intervention set Jason up for failure as his prognosis for regaining oral speech was poor based upon his etiology and the presence of the tracheostomy.

Pre-implementation interactions between Jason and his wife were also problematic in that May initiated but seldom maintained topics for more than one or two conversational turns and frequently asked Jason open-ended questions without offering acceptable means of response. Jason's role as passive participant was perpetuated as May anticipated his every want and need, focused on medical

problems and appearance, and directed the majority of her conversation toward other participants. Furthermore, because May spent the majority of the time at Jason's bedside, there were few novel or meaningful experiences to converse about. Thus, she tended to rely upon the narration of ongoing, largely unvarying events.

The interactive behaviors of other participants appeared to be guided by their perspectives regarding Jason's medical condition and low expectations for response. Initial perceptions that Jason was comatose or existing in a vegetative state led many participants to restrict communicative opportunities by employing interfering non-verbal communicative behaviors, demonstrating unusual proxemics, and avoiding one-on-one interaction. During the pre-implementation phase, even the investigator failed to maintain eye-contact with Jason or directly interact unless other participants were present. These behaviors were attributed to both a lack of familiarity with Jason, and an attempt to "save face" in the probable event that he offered no response. Unfortunately, avoidance of one-on-one interaction with Jason precluded any potential communicative attempts on his part.

Outside visitors physically distanced themselves from Jason further limiting his communicative opportunities. As suggested by Light (1988), the interactive abilities of

non-speaking individuals are largely influenced by the proximity of speaking partners especially when the person must rely on subtle gestures to communicate. When Jason's in-laws and brother positioned themselves far from his bed, they were unable to observe and respond to minimal changes in his behavior. Jason, on the other hand, was unlikely to attempt interaction when individuals were outside of his visual field.

Finally, staff members generally ignored Jason or treated him as a prop around which to center conversation. They discussed him as if he was not present and did not attempt to communicate non-verbally with eye-contact or subtle gestures. It was also noted that nurses failed to prepare him for invasive procedures with simple explanations, natural gestures, or physical prompts to increase his comprehension of what would follow. Unfortunately, by ignoring Jason, staff members failed to notice, interpret, or respond to his reactions. During the pre-implementation phase, this "dehumanization" was perpetuated by Jason's lack of response to invasive or painful procedures, physical helplessness, speechlessness, and inability to control bodily functions. Unfortunately, aside from having negative psychological ramifications, being ignored or treated as an object severely limited Jason's interactive opportunities and decreased the

likelihood he would attempt to effect changes in his communicative environment.

#### Post-implementation Interactions

Analysis of post-implementation data reveals that while there was a great deal of variability across observed dyads, interactions between Jason and the SLP, family members, and other participants were generally more evenly balanced. Jason's increased adaptive behaviors, communicative signals, and rate of response were largely responsible for this reciprocity. However, subtle variations in speaking partners' perspectives and interactive strategies provided communicative opportunities that were not available during the pre-implementation phase.

As documented in Results (Chapter IV), the SLP spontaneously began employing more facilitative strategies such as decreasing length of utterance, issuing fewer directives, and asking yes/no questions that were more likely to elicit response than open-ended questions. Perhaps his most effective interactive "strategy" was increasing the pause time or silence between utterances as this provided Jason the time and opportunity to respond. This finding was consistent with that of many investigators in the field of AAC who have documented significant increases in the initiation and response rates of severely disabled individuals provided silences or expectant pauses



during interactions with natural speakers (Halle, Baer and Spradlin, 1981; Light, Collier, and Parnes, 1985). The SLP's employment of therapeutic techniques also became more productive as he gained familiarity with Jason's past preferences and observed the facilitators engaging in novel activities that elicited positive responses. The introduction of peer facilitators and changes in Jason's daily routine provided the therapist relevant topics and concrete experiences about which to converse. Additionally, Jason experienced some degree of success during post-implementation therapy sessions as the therapist experimented with sensory stimulation techniques and positively reinforced minimal responses to stimuli.

The dynamics of interaction between husband and wife were also modified over the course of the investigation. May was motivated by changes in Jason's level of responsiveness and subsequently employed many of the same techniques she observed during facilitator-based intervention sessions. Furthermore, instead of pre-empting Jason's communicative opportunities by anticipating every want and need, May began ascribing intentionality to his responses and acting upon non-verbal signals. There were several documented occurrences of sustained interaction as May maintained topics over three or more conversational turns. As was the case with the SLP, the introduction of novel activities and meaningful stimuli or "props" (i.e.,

slides of home and family, past food preferences, music) allowed May to generate conversation about shared referents and experiences.

The investigator's early post-implementation interactions were enhanced by the constant presence of Jason's wife and son. May and Jason Jr. provided information about Jason's past preferences, experiences, and personality while maintaining a steady stream of conversation when he failed to respond. As the study progressed, Jason's increased rate, frequency of response and emerging affective behaviors further eased the investigator's interactive efforts. Conversely, changes in the investigator's demeanor and interactive style, along with her frequent attempts at humor appeared to motivate many of Jason's responses.

While various participants continued to exhibit negative interactive patterns during the post-implementation phase, there were documented changes in the behaviors of several staff members. Much of the increased attention and responsiveness afforded Jason by aides, nurses, and the lab technician (who performed the arteriogram) can be attributed to actual changes in his behavior. However, "word of mouth" about Jason's behavior, increased attention from the investigator and therapists, and an emphasis on Jason's past interests and personality also contributed to more reciprocal interactions. Jason's

participation in the investigation along with the constant presence of facilitators resulted in more focused attention from staff members who entered the room throughout the day. Jason's wife and son frequently discussed the service delivery model with various staff members, further increasing the likelihood they would more closely attend and subsequently respond to subtle changes in Jason's behavior. Finally, it appears that exposure to Jason's past interests, preferences, and personality via activities that incorporated his favorite music, pictures, and slides allowed staff members to view him as a "person" rather than solely a "patient". Subtle changes in the reactions of aides and nurses (i.e., ascribing intentionality to non-verbal behaviors, responding to his activation of an augmentative device), provided Jason a degree of environmental control he was unable to achieve during the pre-implementation phase.

In sum, the facilitator-based service delivery model was designed to minimize the cognitive, communicative, and physical limitations imposed by Jason's neurological condition and the characteristics of his communicative environment. The model did not, however, directly address the interfering behaviors, interactive styles, or strategies of other participants. It appears that the implementation of facilitator training and communicative intervention within a natural environment along, with

Jason's ensuing behavioral responses, led to reciprocal changes in the behaviors of other participants and positively affected Jason's ability and motivation to respond. Quantitative measures and qualitative data based upon descriptive observation and participant reports of Jason's increased use of non-verbal signalling behaviors indicate that the cycle of learned helpless and passivity may have been interrupted by the implementation of the facilitator-based service delivery model as well as second-order changes in the communicative environment.

## CHAPTER VI: CONCLUSIONS AND IMPLICATIONS

The overall findings of this investigation indicate that each of the three components of the service delivery model- sensory stimulation, assistive technology, and facilitator training, was effective to some extent in bringing about changes in Jason's behavior. Furthermore, the reciprocal relationship between Jason's emerging responses to intervention and subtle changes in the perceptions and behaviors of other participants led to more effective patterns of interaction within the communicative environment.

The results of this investigation suggest numerous clinical implications and directions for future research with the profoundly brain-injured population. This chapter begins with a discussion of the methodology followed by suggestions for more effective rehabilitation with STR clients.

### Methodological Issues

#### Quantitative Measures

The investigator employed the Western Neuro Sensory Stimulation Profile (WNSSP) to obtain quantitative measures of the subject's behavior because it was the only standardized assessment tool designed especially for the STR population. The instrument was deemed adequate for measuring improvement and subtle changes in cognitive, motor and communicative behavior, as well as for

identifying preferred modalities for input. However, the scoring system was limited and there was no means of accounting for behaviors observed in other situational contexts. Nonetheless, the WNSSP is recommended as a valuable assessment tool for clinicians working with profoundly brain-injured persons when supplemented with qualitative measures such as descriptive observation, participant interviews, and video-recording.

#### Ethnographic Measures

The ethnographic methods employed during all phases of the investigation supported the quantitative findings of the WNSSP and provided invaluable contextual information. Extensive participant observation, ethnographic interviews, video-recording, and artifactual analysis enabled the investigator to identify and explore extrasituational variables that interacted with Jason's brain-injury to affect his performance.

A major strength of the methodology was that it allowed for the implementation of training and intervention within the subject's natural environment. Family members, staff, and therapists were introduced to novel therapeutic techniques and were able to observe and comment on the subject's responses to intervention. A renewed focus on the subject enabled all participants to view him as more of an individual than solely a patient.

While the employment of a descriptive methodology was appropriate to this investigation, the complexity of the service delivery model made it difficult to isolate and quantify the effects of each "experimental" variable on the subject's behavior.

### Clinical Implications

The results of this investigation indicate that sensory stimulation is an essential component of an intervention program designed to optimize the rehabilitative potential of the STR individual. Multimodality stimulation based on the phylogenetic sequence of development should be attempted regardless of initial diagnosis (unless contraindicated in the opinion of the physician) as profoundly brain-injured clients, like Jason, often demonstrate far more improvement than initially predicted. Furthermore, denying therapy based on a precipitously assigned diagnostic label can minimize the likelihood that the client will ever receive optimum intervention.

In addition to structured sensory stimulation, subtle changes in the physical environment (i.e., increased lighting, novel auditory stimuli) and increased attention from all participants may have contributed to the changes in Jason's behavior during the post-implementation phase. Incidental stimulation via modification of the physical environment can provide normal and necessary sensory input

to the STR patient (e.g., covering the walls with visually stimulating prints and photographs, adjusting lighting to simulate the time of day, playing favorite music, presenting a favorite cologne). Additional stimulation can be provided by frequently touching, talking to, and adjusting the position of the STR individual.

The assistive devices utilized over the course of this investigation were designed to provide Jason some degree of control and the opportunity to actively participate in his environment. A variety of switches should be made available to STR patients so that they can activate call buttons, lights, radios, and televisions. Jason was also provided access to simple communication devices which enabled him to express his wants and needs. Unfortunately, these devices are not available in many long-term care facilities. Profoundly brain-injured persons who do not have access to communicative devices must employ subtle gestures and unconventional signals to communicate. Thus, significant others and staff members should be encouraged to acknowledge and act on any non-verbal signal, whether it appears intentional or unintentional.

The findings of this investigation indicate that Jason's lack of mobility precluded his participation in resident activities that might have provided valuable opportunities for socialization and environmental stimulation. In order to facilitate active participation



through community interaction, STR clients should be provided with means of mobility, taken from their rooms throughout the day, and placed in areas of high resident activity.

#### Implications for Professional and Non-Professional Training

The Speech-Language Pathologist who participated in this investigation was ill-equipped to deal with non-responsive clients. To better prepare speech-language pathology students who might eventually work with the STR population, university training programs should include coursework relating to communicative intervention with profoundly brain-injured persons. Based on the review of the literature and the findings of this study, some of the issues that students should be made aware of include: rehabilitative and interactive problems, appropriate short and long term goals, the benefits of sensory stimulation, augmentative communication and environmental modification, and the necessity of support personnel. The findings of this study suggest that non-professionals can also be trained to employ basic therapeutic techniques with STR patients. Family members, friends, and peers who are interested in providing additional services should be provided inservices, training and materials by the SLP.

In terms of socialization, the employment of peer communication facilitators minimized the isolation Jason had experienced in the long-term facility and provided

additional environmental stimulation. Based on these findings, it might be beneficial to encourage willing residents to visit STR patients throughout the day, providing orienting information, reading to, or simply describing the events of the day to the client.

#### Psychosocial Implications

The results of this investigation suggest that contextual and affective variables operate along with cognitive and motor deficits to affect the STR client's rehabilitative progress. This finding is consistent with that of Mendoza and Damico (1991) who discovered that the willingness of an adult with Locked-in-syndrome (LIS) to utilize an augmentative system was influenced not only by physical condition, but intrinsic variables (i.e., depression, hopelessness, learned helplessness), and extrinsic factors (i.e., lack of responsiveness on the part of caregivers, unrealistic goals, poor prognosis for recovery). In order to minimize negative variables that interfere with progress, it is essential to design a rehabilitative program that motivates the client by providing some degree of normalization, meaningful activities, and attainable goals.

The results of this study indicate that Jason experienced little success during the pre-implementation phase. Because consistent failure can impact on motivation, leading to hopelessness and depression,

therapeutic activities should be on realistic goals with functional outcomes. The process of external motivation needs to be a step-by-step process with short term objectives that the individual can achieve in a relatively brief period of time. The client should be informed of all goals so that he has something to strive for. When designing therapeutic activities the therapist must consider the personality, preferences, and past experiences of the client. This applies to the selection of stimuli and reinforcers for sensory stimulation and augmentative communication activities as well as the selection of appropriate facilitators. Ongoing ethnographic interviews conducted with significant others can provide invaluable information about the client's background which should be incorporated in activities and related to potential interactants.

Because interpersonal relationships can influence self-perception, self-esteem, and motivation, communication partners should be encouraged to view the client as more than a sick, helpless patient. "Normal", age-appropriate activities that reflect the client's past preferences and experiences can facilitate this process. Staff and family members should also be discouraged from letting diagnosis or poor prognosis for recovery guide their perceptions or treatment of the client.

### Interactive Implications

The present investigation revealed that Jason was often pre-empted from communicative opportunities by individuals who anticipated his wants and needs and employed interfering interactive behaviors. This finding suggests that it is essential to examine the patterns of interaction of other participants in the environment as they can perpetuate underfunctioning and communicative passivity. In order to increase the client's ability to initiate interaction and respond, partners must be cognizant of those behaviors which constitute communication for the particular person. Interactants should also be encouraged to provide opportunities for active communication by modifying both the physical aspects and linguistic structure of communication (e.g., focusing attention on the individual, interacting at eye-level, decreasing length of utterance, providing pause time).

### Directions for Future Research

This investigation was one of a small number to date within the area of AAC that have attempted to evaluate the overall effectiveness of communicative intervention programs with non-responsive, brain-injured adults. The results of the study suggest several avenues of future research with the STR population. The first relates to the recovery patterns of individuals with profound neurological impairments. Long-term studies following the clients from

onset of injury would provide valuable information for physicians, family members, therapists and third-party payers. Because little research has been devoted to individuals who are nonresponsive as the result of acquired neurogenic disorders, there is clearly a need for further investigation.

Another issue that warrants exploration is the efficacy of employing sensory stimulation techniques early on in the recovery process. There is a need to determine the benefits of sensory stimulation with post-acute care brain-injured clients. Based on the finding that sensory stimulation imposed an effective framework for interaction with non-responsive clients, further study is needed relating to the effects of various therapeutic techniques on patterns of verbal/non-responsive interactions. Additional research is also needed to determine appropriate training strategies and techniques for non-professionals.

Finally, there is a growing realization within the field of AAC that many clients are as challenged by social/relational inadequacies as by limitations of physical or cognitive functioning (Warrick, 1988). Because the importance of the partner in interaction has not always been recognized in research to date (Light, 1988), additional descriptive studies are needed which explore the impact of sociocommunicative variables on the functioning of profoundly brain-injured individuals.

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APPENDIX A  
Scoring of WNSSP Test Items

I. Arousal/Attention

1. Arousability: Ease of arousal at beginning of evaluation.

0=Requires repeated presentation of two or more stimuli

1=Requires two or more stimuli

3=Already awake

2. Wakefulness: Longest period of time patient remains awake without being re-aroused.

0=10 minutes or less

1=11-20 minutes

2=21 or more minutes

3. Eye Contact: Patients eye-gaze during the majority (50%) of the session.

0=Eyes closed

1=Eyes opened but not focused on examiner

2=Eyes focused on examiner (50%) or more

9=Physically unable to open eyes (CN III paralysis)

4. Attention to Task: Patients ability to attend to tasks.

0=Attends less than 50% of the time

1=Attends 50% or more of the time

II. Auditory Response

Localization

5. Voice: Patients response to introductory remarks at beginning of session.

0=No response

1=Undifferentiated response

2=Differentiated response

6. Sound: Patients best response to non-verbal sound during the evaluation.

0=No response

1=Undifferentiated response

2=Differentiated response

Comprehension

7-12. Auditory Commands: Patient's ability to follow single-stage auditory commands.

0=No response

1=Incorrect response

2=Cued, delayed response

3=Cued, prompt response

4=Spontaneous, delayed response

5=Spontaneous, prompt response

## Appendix A (continued)

## III. Expressive Communication

13. Vocalization: Patients best vocal utterance.

0=No response

1=Produces spontaneous, non-meaningful vocalization

2=Produces spontaneous, inappropriate verbalization or mouthing of words

3=Vocalizes on command; mouths words or verbalizes appropriately either spontaneously or on command

14. Facial/Gestural Communication: Patients use of facial expression and gesture for communication.

0=No response

1=Uses one gesture/facial expression with at least primitive intent

2=Uses more than one gesture/facial expression with communicative intent

15. Yes/No Response: Patients ability to produce differentiated "yes" and "no" responses.

0=Neither response observed

1=Either "yes" or "no" response observed

2=Both responses observed

## IV. Visual Response

16-19. Horizontal Tracking: Patients ability to follow stimuli visually through the left and right visual field.

0=No response

1=Follows from midline to left

2=Follows from midline to both sides

3=Follows across midline from one side to the other

20-22. Vertical Tracking: Patients ability to follow stimuli visually through the upper and lower visual fields.

0=No response

1=Follows in one direction

2=Follows in both directions

23-27. Written Commands: Patients ability to follow single stage written commands.

Score 0-5 as defined for auditory commands (items 7-12).

28. Tactile Response: Patients best response to tactile stimulation.

0=No response

1=Undifferentiated response

2=Differentiated response

29. Oral Stimulation: Patient's responses lip stimulation

0=Withdrawal/abnormal reflexes present

1=Primitive reflexes present

2=Tolerates stimulation

## Appendix A (continued)

## Tactile comprehension

30-32. Object Manipulation: Patients ability to demonstrate conventional use of common objects.

0=No response

1=Holds/releases object

2=Moves object/uses object inappropriately

3=Reaches for/pushes away object

4=Uses appropriately, cued

5=Uses appropriately spontaneously

9=Both arms splinted or casted \*(not scored)

## VI. Olfactory Response

33. Smell: Patients response to olfactory stimuli.

0=No response

1=Undifferentiated response

2=Differentiated response

9=Not applicable (patient has tracheostomy)

## APPENDIX B

### Schedule of Observation, Video-Taping and Audio-Taping

O=Observation

V=Video-Taping

A=Audio-taping

#### Pre-Implementation:

July 8: OT/SLP therapy (O)  
 July 9: Nursing home (O), OT/SLP therapy (V)  
 July 10: Residents (O)  
 July 13: Nursing home, OT/SLP therapy (O)  
 July 14: Nursing home, OT/SLP therapy (V)  
 July 15: OT/SLP therapy (O)  
 July 17: Nursing home, OT/SLP therapy (O)  
 July 18: Nursing home, OT/SLP therapy (O)  
 July 20: Nursing home, OT/SLP therapy (O)  
 July 21: OT/SLP therapy (O), tour of nursing home  
 July 22: Nursing home, OT/SLP therapy (O)  
 July 24: Nursing home, OT/SLP therapy (O)  
 July 27: Initial interview potential facilitators (A), initial WNSSP (V)  
 July 30: Initial interview Speech Language Pathologist (A)  
 August 3: OT/SLP therapy (O)  
 August 11: Potential facilitators (O)  
 August 12: OT/SLP therapy (O), Interview with May (A)  
 August 14: Potential facilitators (O)  
 August 16: OT/SLP therapy (O)

#### Facilitator Training Period:

August 17: Nursing home (O), Interview Dan and Frank (A)  
 August 18: OT/SLP therapy (O)  
 August 19: Jason (O)  
 August 20: OT/SLP therapy (O)  
 August 21: OT/SLP therapy (O)  
 August 31: Frank and Dan's introduction to Jason (V), inservice (V)  
 September 1: Facilitator training (V)  
 September 3: Facilitator training (V)  
 September 4: Facilitator training (V)  
 September 8: Facilitator training (V)  
 September 9: Nursing home (O)  
 September 10: Visitors, training session (V)  
 September 11: Training session (V)  
 September 12: Jason (V)  
 September 15: OT/SLP therapy (V)  
 September 20: Follow-up interviews Frank, Dan, May (A)  
 September 21: Sensory stimulation hands-on (V)

## Appendix B (continued)

## Post-Implementation:

September 22: OT/SLP therapy (V)  
 September 24: Sensory stimulation Dan (V)  
 September 25: Sensory stimulation Frank (V)  
 September 26: Interview May (A)  
 September 27: Sensory stimulation Frank (V)  
 September 28: Jason sleeps, Interview Dan (A)  
 September 29: Jason sleeps  
 September 30: Assistive Technology Dan and Frank (V)  
 October 1: Sensory stimulation Frank (V)  
 October 5: Assistive Technology Dan and Frank (V)  
 October 6: Sensory stimulation Dan (V)  
 October 8: Sensory stimulation Frank (V)  
 October 9: Assistive Technology (V)  
 October 11: Sensory stimulation (V)  
 October 12: Communication board, Sensory Stimulation(V)  
 October 13: Arteriogram (V)  
 October 14: Sensory stimulation Frank (V)  
 October 15: Sensory stimulation Frank (V)  
 October 16: Jason (O)  
 October 17: Sensory Stimulation (V)  
 October 18: Jason (O)  
 October 19: Sensory stimulation Frank (V)  
 October 20: Assistive technology Dan (V)  
 October 21: Jason (O)  
 October 22: Sensory stimulation Frank (V)  
 October 23: Assistive technology (V)  
 October 25: Jason (O)  
 October 26: Family visit, Assistive Technology Frank(V)  
 October 28: Interview Son, P.T.Evaluation (V)  
 October 29: Sensory stimulation Dan (V)  
 October 30: Sensory stimulation Dan (V)  
 October 31: Sensory stimulation Frank (V)  
 November 2: Sensory stimulation Frank (V)  
 November 3: Sensory stimulation Frank (V)  
 November 4: Augmentative Device (V)  
 November 5: Augmentative Device Dan (V)  
 November 6: Assistive Technology Frank (V)  
 November 8: Sensory stimulation Frank (V)  
 November 9: Jason asleep, Frank visits (V)  
 November 10: Interview son (A)  
 November 11: Sensory stimulation Frank (V)  
 November 12: OT/SLP therapy (V)  
 November 13: Sensory stimulation Frank (V)  
 November 14: Assistive technology Frank (V)  
 November 15: Assistive technology Frank (V)  
 November 16: Sensory stimulation Frank (V)  
 November 17: Sensory stimulation Frank (V)  
 November 19: Interview Activity Director (V) Sensory stimulation Frank (V)

## Appendix B (continued)

November 21: Sensory stimulation Frank (V)  
November 23: Interview May (A)  
November 30: Final interview SLP (A)  
December 6: Final interview son, May, Frank (A), sensory  
stimulation Frank (V)

APPENDIX C  
Letters of Consent For Participation in Investigation

COMMUNICATION FACILITATION WITH SLOW-TO-RECOVER PATIENTS

**Facilitators**

LETTER OF CONSENT

I give my permission to Alisa Mendoza to include me in a research study which will require the video-taping and audio-taping of my interactions with residents and staff at the \_\_\_\_\_. I understand that these tapes are for research purposes only and will not be released to the general public for any reason without my permission. Furthermore, I agree to participate in a facilitator-training program which is being carried out by the Louisiana State University Augmentative Communication Clinic. All video and audio recordings collected during the time of the investigation may be utilized for research purposes only and are not to be released to the general public.

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COMMUNICATION FACILITATION WITH SLOW-TO-RECOVER PATIENTS

**Spouse**

LETTER OF CONSENT

I give my permission to the researchers of the Louisiana State University to involve \_\_\_\_\_ in a research project. I will allow Alisa Mendoza to video-tape and audio-tape my husband's interactions with residents, staff and significant others at the \_\_\_\_\_. I understand that these tapes are for research purposes only and will not be released to the general public for any reason without our permission. Furthermore, I am aware that this project involves a facilitator-training program which will require the use of sensory stimulation and augmentative communication techniques carried out by residents of the facility. I understand that the Investigator will supervise all intervention sessions and avoid any procedures that may prove harmful to \_\_\_\_\_. I also give permission for the release of any relevant medical or therapeutic records regarding \_\_\_\_\_. Information obtained from these records will be utilized for research purposes only.

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## Appendix C (continued)

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COMMUNICATION FACILITATION WITH SLOW-TO-RECOVER PATIENTS

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**Administrator**LETTER OF CONSENT

Permission is granted to the researchers at the Louisiana State University to conduct an investigation utilizing specific residents of the \_\_\_\_\_. The following research activities may take place within the facility:

- 1) Video and audio-taping of staff members and residents who sign release form.
- 2) Observation within all public areas of the facility.
- 3) Access to the Subject's therapy or medical records following written consent from caregivers.
- 4) Use of all data collected within the facility for research purposes.

The researchers may release no information to those outside of the research community without first obtaining permission from the administration of the \_\_\_\_\_. The staff of the facility assumes no liability for any mishaps which occur in direct relation to the investigation.

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APPENDIX D  
Content of Facilitator Training Sessions

Session One: (August 17)

**Initial Interview and Inservice**

Context: 60 minutes in the Facilitators' room

- Objective 1: To determine the extent of facilitator knowledge about subjects's background, medical condition, and functional status.
- Objective 2: To gather facilitator perspectives regarding subject's communicative status and prognosis for recovery.
- Objective 3: To provide general overview of profoundly brain-injured population, communicative goals, multimodal aspects of intervention

Informational Content:

- A. Nature of profound brain Injury, rehabilitative dilemmas and rehabilitative needs
- B. Problems with current service delivery models
- D. Primary goals of intervention--environmental control, interaction, functional communication
- A. Impact of augmentative communication use on communicative opportunities. Aids and devices as tools
- E. Role of communication partners

**Session Two (August 31):**

**Introductory session**

Context: 65 minutes in subjects room

- Objective 1: To inform subject about nature and goals of the project.
- Objective 2: To Introduce Subject and family members to facilitators.
- Objective 3: To briefly discuss and demonstrate the augmentative and sensory stimulation techniques that will be utilized over course of investigation.

Informational Content:

- A: Description of subject and facilitators' roles in investigation
- B: Sensory stimulation to facilitate neurological recovery and activation of association areas of brain
- C: Augmentative techniques to provide environmental control and facilitate early communicative function

Materials:

siren and switch, slide projector, fan and switch, sensory stimulation kit.

Appendix D (continued)

**Session three (September 1):**

**Microswitch technology**

Context: 60 minutes in Subject's room

Objective 1: To familiarize facilitators with control interfaces that can be activated via minimal body movement

Objective 2: To familiarize facilitators with adapted battery operated appliances

Objective 3: To discuss switch placement and optimum positioning of subject for appliance activation.

Informational content:

A: Switch activity hierarchy

B: Interfacing switches and reinforcers

Materials

tape recorder, fan, vibrator, siren

Wafer Switch (Tash), Plate Switch (Don Johnston)

Wobble Switch (Prentke Romich), Button Switch (Tash)

Big Red Switch (Steven Kanor), Vibrating Switch (Steven Kanor), Voice Activated Switch (Steven Kanor)

**Session four (September 3):**

**Environmental Control Units**

Context: 65 minutes in subjects room

Objective 1: To introduce Environmental Control Units (ECUs) that enable the subject to control electrical appliances such as lights, television and radio.

Objective 2: To familiarize facilitators with concepts of active participation and turn-taking via augmentation

Materials:

Television, radio, slide projector, Environmental Control Unit (ECU) (Prentke Romich)

Ablenet Control Unit (Ablenet)

Slide Projector Interface (Tash)

**Session five (September 4)**

**Low technology communication systems:**

Context: 50 minutes in Subject's room

Objective 1: To familiarize facilitators with non-electronic augmentative aids expressly designed for communicative purposes.

Objective 2: To introduce language/message symbol options (orthographic symbols, pictorial representations)

Objective 3: To provide overview of selection techniques (direct, scanning)

Materials

Dial Scan (Don Johnston)

IntroTalker (Prentke Romich)

Yes/No Indicator (Zygo)

Appendix D (continued)

**Session six (September 8):**

**High technology devices**

Context: 55 minutes in subject's room

Objective 1: To familiarize facilitators with electronic devices expressly designed for communicative purposes.

**Materials:**

The Liberator (Prentke Romich)

Minspeak Communication Symbols (Prentke Romich)

Wobble switch (Prentke Romich)

**Session seven (September 10):**

**Introduction to Sensory stimulation techniques**

Context: 60 minutes in subjects room

Objective: To familiarize facilitators with goals of sensory stimulation and introduce techniques designed to help subject progress from generalized to localized level of response

**Informational Content:**

a. Introduction to "sensory stimulation kit" and contents

b. Discussion of progression of sensory stimulation presentation.

**Materials:**

Sensory stimulation kit

**Session eight (September 15)**

**Sensory stimulation demonstration**

60 minutes in Subject's room

Objective 1: To demonstrate appropriate selection and presentation of sensory stimuli with the Subject.

Objective 2: To demonstrate appropriate positioning of subject for optimal response.

**Materials:**

Sensory Stimulation Kit

**Sessions nine and ten (September 20, 21)**

**Hands-on technology and sensory stimulation**

Context: two 60 minute sessions in subjects room

**Session nine**

Objective 1: To provide facilitators hands-on practice with sensory stimulation and assistive technology.

Objective 2: To assure both facilitators could independently manipulate sensory stimulation kit and apply assistive technology with minimal assistance from investigator.

**Materials:**

Sensory stimulation Kit, Wobble switch (Prentke Romich),

Plate switch (Don Johnston), fan, tape recorder, siren

Introtalker (Prentke Romich)

APPENDIX E  
Initial Inservice With Facilitators

- I: Before we start anything I wanted to ask you, have you ever talked to Jason before?
- D: I have.
- F: I haven't, I've been to his room but I have not talked to him.
- I: You have ( to D.) I also wanted to get your initial impression. I know you might only have seen him Frank.
- F: I've seen him, but listening to Dan, uh, Dan has visited him a lot more than I have. I guess I'm a busy person.
- D: The first time I went in and saw him he had just got here. I guess it might have been 2-3 weeks. Um and he wasn't responding to anything. I think right now he's kinda going through different spells. He'll respond to different people, sometimes he won't. Sometimes he'll respond to his wife and Pookie sometimes he'll respond to you and sometimes he'll have a spell where he won't respond to anything.
- I: What do you know about him Frank?
- F: He's comatose in some ways, uh, I remember when he first came, no response at all. I heard that there was a cutoff of oxygen to his brain and that was causing all this. In my case it was a fall, that was damaging but that's not like a dying brain. There was a part of his brain that died and it'll never come back. But it's already been a long time and what little more he's gonna learn is going to be in time.

APPENDIX F  
Initial Inservice and Demonstration

- I: I'll tell you what we're looking at right now. Jason doesn't communicate and even though he might eventually use an electronic communication system he doesn't have the motor ability right now. He has people talking at him and he'll respond every once in a while, but what we're looking at is even getting him to a point where we walk in the room and he responds in some way. Right now his problems might be compounded by the fact that he might be angry or depressed. He hasn't been out in two months at least. He's probably pretty angry, I mean he's got people talking to him all day long like he's two or three years old. With you all coming in he'll have some adult company. I can't really see you treating him like a child or anything like that.
- F: Uh, I understand what you're talking about, the anger and frustration, cause I went through all of that.
- I: Something else, in the long run if May knew that there was someone else in the home looking out for him maybe she could not feel all the pressure and could go to doctors' appointments, ya know her back hurts. She wouldn't feel guilty if she had something else come up you know. I think with you coming in it will address emotional things, show you have some interest. I think it will ease her mind in that she'll know you may be able to look in every once in a while and if he looks to be distressed... The thing with people like Jason is a lot of times the therapist won't even work with them. They say "he's not even doing anything, we'll wait until he does." Sometimes if you can get in there early, you can do something. We want to try to get him more active in his environment now. Right now he has people coming in and doing things for him. Really what your job would be would be to come in and give him that control and hopefully he would start interacting more than he does now. What we want to do is, I have all sorts of devices that can control things from the bed, like you do from your chair. I think it's important to give him back some of that control.

## Appendix F (continued)

F: I've seen all these gadgets before. They gave me extensions to do for me to eat with they were a foot long. I learned a lot of things to do myself since I've been in this nursing home.

I: I bet it was a big thing for you to gain back some of your **independence**. Jason's family is great but they still have a tendency to do everything for him. Someone from the outside might be able to hold back until he communicates. You get into that habit where you don't work very hard because it becomes easy to get things and that's where I think Jason might be. The littlest thing he does gets him something.

D: I think in my case when I go home for the weekend. My mom, she lives alone since my dad died four years ago. Um whenever I go home to stay she kinda babies me. Ya know and I get down on her. I say, mama I want to do it, I can do it mom, back off, But I gotta tell her ya know.

I: Your job in the next few months is to prepare him, get him ready to use one of the more advanced systems. Let him communicate with people his age and work on some simple movements like turning his head. The hypothesis is that by coming in and doing some of these things we'll start seeing changes in his level of awareness, motor skills and things like that. With him actively manipulating things in his environment and being stimulated. **I feel that with your encouragement we might see quicker results just in little things which will help him to communicate better** because I'm looking at communication, little things we take for granted like moving our heads or our eyes...

It's also hard right now for you Frank to communicate with him, for any of us, cause he's not putting forth enough signals where it's natural to talk to him. I want to see if after two months of working with him it becomes a little easier to communicate with him. And then other people in the home, does it carry over to other situations. I think you are the ones to do it. So we would set up the environment so that at least he could have control over things and more stimulation. Like something real simple, right now he doesn't have control over anything. We can take a switch like this and just put it by his head or cheek, and then he can turn on the slide projector, fan, light or siren, something he couldn't do before cause he couldn't move

## Appendix F (continued)

his hands. Like if you (Frank) hadn't gotten back the movement in your hands or all the remote controls you have by your bed. It's like that with Jason right now. His head movement is real minimal. We would hope that by using something like this, by maybe clipping (fan) it to his bed, we could increase head movement and you would be the ones to encourage him...something like that. Okay Jason, move your head, then you keep moving the switch away. After doing this everyday we would hope to see increased head movement and the same goes for hand movement there are switches we can use for all parts of the body.

APPENDIX G  
Introductory Session

- I: (To Jason) Ya know how I've been coming in here, just kinda watching you? Well I've been planning a research project. What I wanna do is have Dan and Frank start coming in here and working with you. Since you've been having all these therapists, I figured it would help if you had just regular people come in and work with you on some of the things the therapists aren't working on, like turning your head more, your eyes. They'd be working with all the environmental controls I've been bringing in to let you turn on the lights, the T.V. all that, after I teach them to use it. We've got all the slides that came in and we can look at those while we're here. You've met Dan before huh?
- J: No response, stares ahead
- I: The purpose of the study is that alot of people in your position don't get therapy, so I was thinking, who could we get to work with them? Someone like Dan or Frank working with you to see if any improvements occur. Frank had a trach before and he had a stomach tube so he's already been through a lot of the things you're going through, speech things so he already knows how you feel. You think that'll be okay if they come in?
- J: No response, stares ahead



APPENDIX H  
Descriptions of Assistive Technology Equipment

Round Pad Switch

Operated by pressing the top surface with 360 degree activation. The switch is approximately 3" in diameter and 1/2 inch thick with both tactile and auditory feedback upon activation.

Wafer Switch

This thin membrane switch has no moving parts and is operated by pressing a colored circle in the middle of the switch. It can be activated with light to medium pressure but provides no auditory or tactile feedback.

Voice Activated Switch

The switch can be activated via voice or sound and sensitivity can be adjusted. The switch is battery powered and requires 1/4" plug or 1/8 " adapter.

Infrared Switch

Sends out infrared beam which when interrupted by body movement (i.e. eyeblink) activates the electronic switching. This three piece unit includes a control module, receiver and speaker wire/phone jack.

Plate Switch

This general purpose switch provides an audible click for feedback, requires 3 oz. of pressure for activation and can be mounted in a variety of ways. The switch can be placed on its side and activated with a sliding or downward movement.

L.T. Switch (Light Touch)

This switch is similar in appearance and function to the Plate switch, however requires a lighter touch (3/4 oz.) for activation by individuals with limited strength.

Mounting Switch

This lightweight (1 oz) switch can be mounted at head or chin level. The round, cushioned lever provides presents an audible click when activated.

Universal Switch Mounting Kit

This mounting system allows for quick, temporary placement of a variety of switches in many positions. An adjustable arm attached to a one-piece clamp tightens onto a table, wheelchair, or bed rail. One flip of a side lever allows for easy placement and removal.

## Appendix H (continued)

### Wobble Switch

Similar in appearance to a joystick, this lightweight (1.5 oz) switch can be activated via any gross body or head movement from any direction of the switch. Upon activation it provides an audible click.

### Slide Projector Control

This interface links a single switch to most models of Kodak Carousel slide projectors. A 5-prong plug connects to the remote control input port on the slide projector. Once connected, each switch activation and release progresses the slide.

### Battery Adapter

This home-made device enables switch activation of any battery operated appliance (e.g. fan, siren, radio). A copper disk soldered to a 1/8 inch mini plug and wire. When the disk is placed in the battery compartment, the flow of current is interrupted until switch activation on the other end.

### Touch Plate Switches

A variety of large red switches with yellow activation plate and 1/4" Jack and plug. They are specially designed with a wide range of responsiveness and sensitivity. The basic 3" x 5" Touch Plate Switch and 5" x 8" Vibrating Plate switch were used during this investigation. The vibrating switch provides vibrotactile stimulation when the plate is depressed.

### Cassette Recorder

This battery operated cassette player is adapted with a battery interrupter for use with a switch. It requires an 1/4" plug or 1/8" adapter.

### Vibrating Pillow

An adapted, soft fabric pillow that provides vibrotactile stimulation upon switch activation. Also requires 1/4" plug or 1/8" adapter.

### Scanning X-10 Powerhouse Environmental Control Unit (ECU)

Can be accessed via a variety of input devices including switches. Enables the user to control 16 appliances via remote activation. Appliances plug into Ultra 4 control modules (Tash).

### Ablenet Control Unit

Similar to Scanning Powerhouse, this device allows control of two appliances via switch activation. Appliances plug into Ultra 4 control modules (Tash)

## Appendix H (continued)

### Yes/No Indicator

8" x 4" device which incorporates two switch or manually operated lighted buttons indicating yes (left) or no (right). Requires AC adapter and 2 1/8 in phone jack/speaker wires for switch activation.

### Dial Scan

The Dial Scan is a rotary scanning communication aid that requires continuous switch activation to move a pointer clockwise or counter clockwise. Overlays are customized based on the communicative needs and abilities of the user. The device accepts two single switches (standard 3.5mm jacks) and contains a dial speed control. The lightweight device is 12" x 12" and requires four (4) "C" batteries.

### Scanning Introtalker

A portable, battery powered speech output communication device which uses speech digitized by the consumer. An 8 to 32 location overlay can be used. Device is 13" x 7" x 3", weighs 5 lbs and can record one minute of speech.

### The Liberator

A portable voice output communication device with tremendous capabilities. For the purposes of this investigation, it was used in its simplest configuration with an eight location overlay direct selection. The device is 13 3/4" x 10 3/8" x 3 3/4" and weighs 7lbs. 14 oz. Ideally it is mounted to the side of the bed or wheelchair. It also has a printer and requires key activation pressure of up to 5 oz. The device has Dectalk synthesized speech which enables the user to communicate as a female, male or child.  
(see Appendix J for sample overlay)

APPENDIX I  
Handout Pertaining To Switch Activity Hierarchy

1. Cause/effect activities

Locate potential switch sites:

- sites of most frequent generalized movement
- controllable movements
- hands, fingers, head movements

Match movement with switch characteristics:

- activation strength needed
- amount of displacement needed
- auditory feedback
- tactile features
- appearance-visual salience
- switch size

Objectives:

- to increase awareness of the environment via development of simple cause/effect relationships.
- to increase initiation and decrease learned helplessness
- to shape generalized into localized movements

Operating microswitch technology:

1. Connect switch to appliance
2. Place switch on body part most likely to move
3. Use cuing hierarchy (verbal prompt, physical prompt)
4. Accept random movements
2. Begin to elicit generalized response
3. Shape responses with social and object reinforcers

2. Technology for communicative purposes

Begin with simple communicative activities using switch activated tape recorder with pre-recorded family message tapes. Incorporate switch activated conversational message tapes for participation in daily interactions.

Objectives:

- to elevate appliance activation skills into more meaningful communication activity.
- to increase attentiveness and discrimination of auditory information

(Adapted from Muehling, et al., 1990)

APPENDIX J  
Sample Liberator Overlay

I Need A Drink	I Love You, May	Pokie, Pokie, Pokie	No One Listens To Me
Who The Hell Is That Screaming and Why Won't She Shut Up	I Gotta Get Out of This Place	Cut The Shit!	I'm Sick Of This Bed

## VITA

Alisa Katz Mendoza obtained her bachelor of science degree in Speech-Language pathology in 1986 and master of science degree in Communication Disorders in 1988, both from the Florida State University in Tallahassee, Florida. She subsequently moved to Shreveport, Louisiana, and was employed as a Speech-Language Pathologist in both a large residential facility and private practice specializing in augmentative communication. In 1989, she married Lee Mendoza and moved to Baton Rouge, Louisiana to begin her doctoral studies. For the next three years, she retained an assistantship in the Augmentative Communication Clinic at the Louisiana State University. Throughout this period she carried out clinical supervision and instruction of Masters students in addition to evaluating and providing intervention to non-verbal clients. She completed her doctoral program in 1996, maintaining a strong interest in Augmentative Alternative Communication. She has a 3 year old son, Alexander and a 2 year old son, Jacob. Ms. Mendoza is currently acting as an Augmentative Communication Consultant in Mobile, Alabama, and will receive her doctor of philosophy degree in August of 1996.

**DOCTORAL EXAMINATION AND DISSERTATION REPORT**

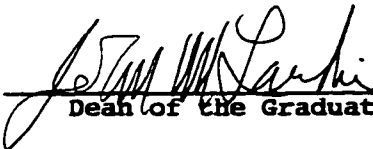
**Candidate:** Alisa J. Mendoza

**Major Field:** Communication Disorders

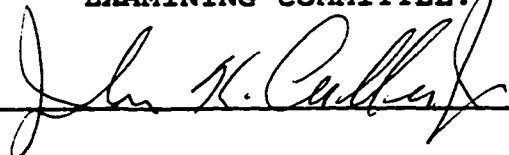
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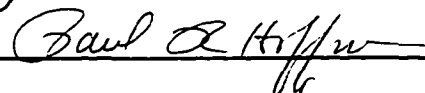
**Approved:**


  
Major Professor and Chairman


  
Dean of the Graduate School


**EXAMINING COMMITTEE:**











**Date of Examination:**

03/22/96